



Assessment of Resident Care in Intermediate Care Facilities for Mentally Retarded

September 6-8, 1977

PUBS
HV
3006
A3
P3
1977

**U.S. DEPARTMENT OF HEALTH,
EDUCATION, AND WELFARE**

Medicaid Bureau

HV
3006
.A3
P3
1977

ASSESSMENT OF RESIDENT CARE
IN INTERMEDIATE CARE FACILITIES
FOR THE MENTALLY RETARDED

Conference Summary

Sponsored by:

THE INSTITUTE FOR MEDICAID MANAGEMENT
MEDICAID BUREAU (MMB),
HEALTH CARE FINANCING ADMINISTRATION
DEPARTMENT OF HEALTH, EDUCATION AND WELFARE

September 6-8, 1977

Kansas City International Airport
Kansas City, Missouri

Prepared by: Pacific Consultants
Under Contract Number
SRS-500-76-0523

(Violet E. Smith, Team Leader)

Preface

The Conference on Assessment of Resident Care in Intermediate Facilities for the Mentally Retarded, one of a series of national conferences being conducted by the Institute for Medicaid Management, was held in Kansas City, Missouri, on September 6-8th, 1977.

Assessment of resident care in Intermediate Care Facilities is one of the primary functions performed by Independent Professional Review teams, mandated by the Code of Federal Regulations 250.24 (a) (2) (3) and (4). This conference, the first nationwide meeting focussing on Independent Professional Review, provided a forum for reviewing State approaches to the implementation of the Independent Professional Review program, in Intermediate Care Facilities for the Mentally Retarded. One hundred participants attended, representing thirty-four States, seven Regions, the Institute of Medicaid Management, the Health Care Financing Administration, State facilities serving the mentally retarded, and several private organizations.

The conference was structured to present a variety of viewpoints and ensure maximum participation by those in attendance. Major addresses were presented by Federal representatives, State representatives, a representative of the President's Committee on Mental Retardation and

a training specialist from the Joint Commission on Mental Retardation. A major feature of the conference was an Action/Reaction Panel, which provided a vehicle for persons directly involved in Independent Professional Review to describe their approaches and experiences. Reactions were provided by a State Medicaid agency representative, a State facility administrator, a spokesman for the National Association for Retarded Citizens, and the audience.

Two hours were devoted to four concurrent workshops each day. Approximately twenty-five persons, broadly representative of the States in attendance, participated in each of the Workshop sessions. Workshop topics corresponded with the two major themes of the conference: September 8th Workshops focused on the Independent Professional Review process and the September 9th Workshops dealt with the issues involved in assessing the quality of care received by individual residents in Intermediate Care Facilities for the Mentally Retarded. The workshops led by State personnel afforded an opportunity for an extensive interchange of State experiences in these two areas.

A draft Manual, dealing with the same basic issues as the conference, and special Workshop materials were used to stimulate and focus the Workshop discussions. Workshop leaders summarized their Workshop proceedings

in presentations to the full conference.

This report provides a summary of the conference. In addition to a detailed agenda of the conference, we have included the text of all speeches; a transcription of the Action/Reaction Panel presentation; and Workshop reports presented to the conference by the Workshop leaders.

Conference participants were asked to evaluate the conference, and a summary of their evaluations is provided in Section Six. Section Seven contains a directory of Conference Participants. The draft Manual was revised to reflect conference input, and it is being published under separate cover.

TABLE OF CONTENTS

	<u>Page</u>
Section I:	
GENERAL SESSION, September 7, 1977	
Welcome: Larry Levinson, IMM	7
Gene Hyde, Acting Regional Administrator, HCFA Region VII	12
Keynote: "The Federal Perspective on the Role of the IPR"	
Robert Silva, Acting Assistant Director, State Operations, Medicaid Bureau	18
Action and Reaction Panels on the IPR	26
"How We Do It" & "How We View It"	
Norma Kelvev, IPR Coordinator, Rhode Island (Action)	28
Angus Wilson, MD, Utah (Action)	35
Robert Decker, Administrator, Idaho State School & Hospital (Reaction)	40
Nancy Searcey, RN, Nebraska (Action)	47
Elmer Pierre, MSW, Minnesota (Action)	50
E. Gene Patterson, National Association for Retarded Citizens, Texas (Reaction)	57
Charlene Seavy, Supervisor, Utilization Control Unit, DPW, Minnesota (Reaction)	63
Luncheon Address: "Evolution or Revolution?"	
Fred Krause, Executive Director, President's Committee on Mental Retardation	68

(continued)

	<u>Page</u>
Section II: Workshop Reports	86
WORKSHOPS: "Sharing State Experiences - Practices, Problems & Solutions"	
Workshop I	
Leader: Keith Cook, Mental Health Coordinator, Medical Services Section, SRS, Kansas	92
Workshop II	
Leader: Polly Stanley, Director, Nursing Home Division, Medical Care Foundation, Georgia	96
Workshop III	
Leader: Linda Cooper, Manager, Long Term Care Unit, Medical Services Section, DSS, Iowa	98
Workshop IV	
Leader: Nancy Searcey, Long Term Care Supervisor, DPW, Nebraska	100
Section III:	
GENERAL SESSION, September 8, 1977	
"Assessing Active Treatment in ICF's/MR"	
Kenneth T. Kuhlberg, Coordinator of Educational Programs, AC/MR-DD, Joint Commission on Accreditation of Hospitals	103
"How to Design & Evaluate a Developmental Plan of Care"	
Warren Bock, Mental Retardation Consultant, MR & DD Division, DPW, Minnesota	123
Kathryn Roberts, Coordinator, Deinstitutional- ization Model Project, DPW, Minnesota	136

(continued)

	<u>Page</u>
Section IV: Workshop Reports	142
WORKSHOPS: "Assessing the Quality of Care"	
Workshop I	
Leader: Marian Lewis, RN, IPR & PMR Coordinator, Minnesota	147
Workshop II	
Leader: Byron Peterson, Psychiatric Social Worker, Medical Services Division, DPW, Nebraska	150
Workshop III	
Leader: William Jones, Superintendent, Belchertown State School, Massachusetts	154
Workshop IV	
Leader: Jan Martin, Coordinator of Occupational Therapy, Georgia Retardation Center	157
Section V:	
CONCLUDING SESSION	
"Future Directions in Quality Assurance"	
Fran Holland	162
Section VI:	
CONFERENCE CRITIQUE	171
Section VII:	
DIRECTORY OF CONFERENCE PARTICIPANTS	177

AGENDA

CONFERENCE ON ASSESSMENT OF RESIDENT CARE
IN INTERMEDIATE CARE FACILITIES
FOR THE MENTALLY RETARDED

September 6-8, 1977

Kansas City International Airport
Kansas City, Missouri

Tuesday, Sept. 6, 1977

6:00-8:00 A.M. Registration

Wednesday, Sept. 7, 1977

8:15-9:00 P.M. Registration

9:00 A.M.-12:30 P.M. General Session

Chairman: Lawrence Levinson,
Acting Director,
Institute for Medicaid
Management, HCFA, HEW

9:00-9:20 A.M. Welcome

Larry Levinson, IMM

Gene Hyde
Acting Regional Administrator,
HCFA Region VII

9:20-10:00 A.M. Keynote:

"The Federal Perspective
on the Role of the IPR"

Robert Silva
Acting Assistant Director,
State Operations,
Medicaid Bureau

10:00-10:30 A.M. Break

10:30 A.M.-12:30 P.M.

Action and Reaction Panels
on the IPR

Action Panel: "How We Do It"

Actors: Norma Kelvey, IPR
Coordinator,
Rhode Island

Angus Wilson,
M.D., Utah

Nancy Searcey,
R.N., Nebraska

Elmer Pierre,
MSW, Minnesota

Reaction Panel: "How We View It"

Reactors: Robert Decker,
Administrator,
Idaho State School
& Hospital

E. Gene Patterson,
National Association
for Retarded
Citizens,
Arlington, Texas

Charlene Seavy,
Utilization Control
Supervisor, DPW,
Minnesota

Moderator: Larry Levinson, IMM

12:30-2:00 P.M.

Luncheon

Luncheon Address:

"Evolution or Revolution?"

Fred Krause
Executive Director,
President's Committee on
Mental Retardation

2:00-4:00 P.M.

Workshops:

"Sharing State Experiences -
Practices, Problems and
Solutions"

(Four concurrent workshops to facilitate an exchange of State ideas, expertise and approaches for implementing the IPR process.)

Workshop I

Leader: Keith Cook, Mental Health Coordinator, Medical Services Section, SRS, Kansas

Workshop II

Leader: Polly Stanley, Director, Nursing Home Division, Medical Care Foundation, Georgia

Workshop III

Leader: Linda Cooper, Manager, Long Term Care Unit, Medical Services Section, DSS, Iowa

Workshop IV

Leader: Nancy Searcey, Long Term Care Supervisor, DPW, Nebraska

4:00-4:45 P.M.

General Session

4:00-4:30 P.M.

Workshop Reports - IPR Process

Keith Cook

Linda Cooper

Polly Stanley

Nancy Searcey

4:30-4:45 P.M.

Wrap-up

Thursday, Sept. 8, 1977

9:00 A.M.-12:00 noon

General Session

Chairman: Matt Brown,
Health Care Program
Analyst, Medicaid Bureau,
HCFA, HEW

9:00-10:00 A.M.

"Assessing Active Treatment
in ICF's/MR"

Kenneth T. Kuhlberg
Coordinator of Educational
Programs, Accreditation
Council for Services for
Mentally Retarded and
Other Developmental
Disabled Persons (AC/MR-DD)

Joint Commission on
Accreditation of Hospitals

10:00-10:15 A.M.

Question Period

Resource: Ginger Hale
Health Care Program
Analyst, Medicaid Bureau

10:15-10:45 A.M.

Break

10:45-11:45 A.M.

"How to Design & Evaluate
a Developmental Plan
of Care"

Warren Bock
Mental Retardation Consultant,
MR and DD Division,
Minnesota DPW

Kathryn Roberts
Coordinator,
Deinstitutionalization
Model Project, Minnesota
DPW

11:45 A.M.-12:00 noon

Question Period

12:00-1:30 P.M.

Luncheon

1:30-3:30 P.M.

Workshops:

"Assessing the Quality
of Care"

(Four concurrent workshops
on the assessment of quality.
The primary task was to
examine and recommend
expansion or revisions of
that portion of the draft
manual which relates to
quality assessment.)

Workshop I

Leader: Marian Lewis, R.N.,
IPR & PMR Coordinator,
Minnesota

Workshop II

Leader: Byron Peterson,
Psychiatric Social Worker,
Medical Services Division,
DPW, Nebraska

Workshop III

Leader: William Jones,
Superintendent,
Belchertown State School,
Massachusetts

Workshop IV

Leader: Jan Martin,
Coordinator of Occupational
Therapy, Georgia Retardation
Center

3:30-4:00 P.M.

Coffee Break

4:00-5:00 P.M.

General Session

4:00-4:30 P.M.

Workshop Reports

Marian Lewis

Byron Peterson

William Jones

Jan Martin

4:30-4:50 P.M.

Question and Answer Period:

"Future Directions in
Quality Assurance"

Federal Discussants:

Fran Holland, Division
of Quality Control

Matt Brown

Ginger Hale

4:50-5:00 P.M.

Closing Remarks

CONFERENCE INTRODUCTION

LARRY LEVINSON

Acting Director,
Institute of Medicaid Management
Medicaid Bureau
Health Care Financing Administration

INTRODUCTORY REMARKS

Larry Levinson

Good morning and welcome to the Conference on Assessing Care of the Mentally Retarded. We plan to keep you busy for the next two days and hope you'll find the experience stimulating and productive.

The Institute for Medicaid Management was established to bring about improved management of the Medicaid program. Those of us at the Institute believe this can be done through a variety of means, and this conference is just one of them. There's something else that we believe the Institute can provide, and that's a forum for the exchange of ideas, the discussion of problems and solutions. To put this in more ambitious terms, we hope to facilitate the transfer of technology between States.

This is the first time in the history of the Medicaid program that a national conference has been held for State review teams. I'm happy to say that the Institute for Medicaid Management is the component that corrected this inadequacy.

I hope that in the future we can have more meetings for reviewers, possibly on subject areas like developing and using patient assessment forms and accompanying instructions. We might also try to have a session

devoted to what quality of care is, and try to crystallize the research and discussion that has gone on now for over twenty years as to how to define quality care.

We have already begun discussion and planning for a meeting on deinstitutionalization - a topic of interest to you and many others.

It's no secret, nor is it disputed, that the quality of care in many nursing homes needs improvement. We view your job as one way to tackle this problem.

It's also no secret that problems generally have more than one way of being solved. We believe that as you discuss some of your problems with team members from other States, you'll find a similarity of problems, but a diversity of solutions.

During these next two days, you'll hear from a JCAH representative on what to look for in assessing care of the retarded and you'll hear a Minnesota consultant tell about designing and evaluating a developmental plan of care. You'll also have opportunity to ventilate your viewpoint in workshops and during question and answer periods.

We hope that when the conference is over, you'll go home full of new approaches and zeal for improving the quality of care for Medicaid nursing home patients.

Now I'd like to take a few minutes to call your attention to the various materials included in the kit

that you were given at registration.

First, there's an agenda which describes all of the activities which are planned for the two days of the conference. Please note that the workshops are numbered and that these numbers correspond with numbers on your badges. The locations of the workshops, by workshop number, are specified on the agenda. In making the workshop assignments, we tried to ensure that there would be broad State representation and approximately equal numbers in each workshop in order to maximize the interchange of experiences. All simultaneous workshops will be dealing with the same subject matter.

Second, there is a copy of the draft manual which will serve as the content basis for the workshop sessions. Chapter II of the draft manual is particularly relevant to today's workshops and Chapter III is the subject of the workshops for tomorrow...I think you will find it helpful to read the relevant chapters prior to the workshop sessions, since one of the objectives of the conference is to secure your input into revising the manual.

Third, as noted in the preface, the manual was developed on the basis of information provided by the five States visited by the contractor. In order to make the revised version of the manual more truly

reflective of practice throughout the United States, we are asking you to provide some key information about the IPR practices in your State. A one page questionnaire has been developed as a basis for securing this information from you. While you are not required to complete the questionnaire, we would appreciate it if you would do so. Please collaborate with your colleagues in filling out the questionnaire form so that we have one completed form per State. Please answer all questions as fully and frankly as possible. While we are asking for State identification on the questionnaire (in order to be able to specify how many different States are included in the final tabulation), the information itself will only be used in aggregated form; that is, individual States will not be identified in the final compilation of State data. If at all possible, we would like to have the completed questionnaires turned in by the end of the coffee break this morning.

All of the remaining materials in the kit pertain to tomorrow's session: the set of materials, entitled Minnesota Developmental Programming System, will be discussed by Dr. Bock: and the conference critique is to be completed at the end of the session tomorrow.

WELCOME

GENE HYDE

Acting Regional Administrator
Health Care Financing Administration
Region VII

WELCOME

Gene Hyde

I am pleased for several reasons to have the opportunity to welcome this group to this conference.

First, of course, I welcome you to Kansas City and sincerely hope that you have a pleasant stay and a successful conference.

Second, I believe this is the first conference in Kansas under the banner of the Institute for Medicaid Management. The Institute, of course, is operated by the Medicaid Bureau, a major component of the Health Care Financing Administration. The Institute approach has proven successful in other program areas. Clearly, the success is attributed to the participants such as yourselves.

Third, the subject matter for discussion at this conference is highly important and very timely as a number of individuals and groups are beginning various efforts to determine how well the Medicaid Program is serving its clients. Finding better ways to conduct Independent Professional Reviews in ICF's/MR and making full use of the information obtained in these reviews is highly critical from a number of stand-points:

- We have to improve the mechanisms now in use to assure that mentally retarded patients are

in fact getting the various services that they deserve and need. The appropriateness, timeliness and quality of that care has to be the number one objective.

- I don't want to dwell on it, but the fact is that periodic IPR visits are required by Federal Statutes and Regulations. Given this fact, and the commitment to see that appropriate and necessary services are being delivered and received takes us quickly to the need to develop more effective ways of conducting IPR's and more effective ways to utilize the information resulting from IPR's to the best interest of the clients.
- I noted in one of the informational pieces about this Conference that Federal requirements would not be specifically addressed and this is good. Accept the idea that IPR's must be performed; recognize the latitude and flexibility that is possible and develop new approaches for using IPR's as a tool to assure that patients are being appropriately served.

Since you will be discussing this activity in great detail during the two days ahead, I would like to spend the few minutes I have left on the fourth reason that I am pleased

to be here today.

The fourth reason is the opportunity to talk briefly about the Health Care Financing Administration.

As you know Secretary Califano announced a major reorganization of HEW on March 8.

This reorganization resulted in the creation of the Health Care Financing Administration as a principal operating agency within HEW. Secretary Califano said in his announcement of the reorganization and I quote:

"The urgent need to place HEW's disparate health care financing mechanisms, especially Medicare and Medicaid, under a single tough-minded, cost conscious administrator has been recognized by President Carter, by the Congress and by the nation's governors. The Health Care Financing Administration will provide basic quality control and will tackle strenuously the problems of fraud and abuse that so severely undermine our government health programs."

HCFA is responsible for providing direction and technical guidance to the efforts to plan, manage and evaluate health care financing programs and policies. HCFA is responsible for operations of the Medicare program and the Medicaid program, as well as a variety of related programs designed to control program costs, assure appropriate utilization of the health services

by eligible individuals and eliminate provider fraud and abuse.

The mission of HCFA, in its simplest form, is to ensure that the best possible care is delivered in the most economical manner to eligible individuals.

The four major program components in HCFA are:

- The Medicaid Bureau
- The Medicare Bureau
- The Health Standards and Quality Bureau
- The Office of Program Integrity

It should be noted that the Federal/State grant-in-aid concept of the Medicaid program has not been changed by this reorganization. The basic Medicaid Statute, Title XIX, is unchanged.

While you may not yet have detected much, if any, change in the Medicaid program as a result of the reorganization, a number of activities are underway or in the planning stage which will enable HCFA to substantially improve the operation and effectiveness of the Department in the various programs. Some of these are:

- Better coordination between programs that previously were scattered throughout various agencies within the Department.
- Consistent policies, where appropriate, in the

Medicare and Medicaid programs.

- Use of the considerable clout provided by the total of expenditures in the HCFA programs as leverage on the health care delivery system to force many things ranging from improved care to cost containment.
- Curtailment of some of the duplications that have existed between the programs.
- Sharing of expertise from people to systems by the programs.
- Consolidated input by the programs into the development of a National Health policy including a national policy on long term care.

These are only a few of the anticipated benefits resulting from the reorganization and creation of HCFA. I am certain that you will hear more about the Health Care Financing Administration in the weeks and months ahead and I hope what you hear will be positive and will be of assistance to you in making the Medicaid program more responsive to the population it is intended to serve.

Again, I hope you have a pleasant stay and a productive and beneficial conference.

KEYNOTE ADDRESS

"The Federal Perspective
on the Role of the IPR"

ROBERT SILVA

Acting Assistant Director
State Operations
Medicaid Bureau
Health Care Financing Administration

"THE FEDERAL PERSPECTIVE ON THE ROLE OF THE IPR"

Robert Silva

This Conference represents a continuation of the dialogue started over a year ago on intermediate care facilities for the mentally retarded (ICF's/MR). The National Governors' Conference Committee on Human Resources and the New Coalition submitted to the Department a report enumerating the substantial difficulties States were facing in attempting to meet the ICF's/MR standards that were to be effective in March, 1977. Subsequent to receiving that report the Department held several meetings with the various public and private groups concerned with care for the retarded in an attempt to establish a set of requirements which were realistic and enforceable and which contributed to the goal of quality care.

The issues not only involved the various groups but received the attention of Secretary Califano and Under Secretary Champion and was one of the first issues faced by Mr. Derzon when he came on board as the Administrator of the Health Care Financing Administration.

Many important items resulted from these discussions. However, two were highly important and they are represented at this Conference:

- 1) involvement of the "front line" people in Federal initiatives; and

- 2) the need to focus on the resident - outcome versus input - the individual affected, not bricks and mortar.

At the outset I'd like to tell the review team members present that we in the Medicaid Bureau consider your roles pivotal in upgrading the quality of care for the mentally retarded. The challenges and responsibilities before you are great but so are the opportunities.

As most of you know, Congress enacted the periodic medical review (PMR) requirements in 1969 after hearing testimony that described "snake-pit" conditions in many nursing homes. Later when ICF services were moved into Title XIX, they modeled the independent professional review (IPR) process after that of medical review. At the same time, Congress for the first time recognized mental retardation as a condition responsive to active treatment and included services for this group of people in ICF's. This made Medicaid funding available for treating the retarded. However, this has not been without some problems, particularly in the area of certifying large State institutions. I'm sure you could expand on that better than I.

The medical/independent professional reviews are unique in Federal law, since they are the only mandatory reviews that require contact with and observation of the

patient as well as a medical record review. I am certain that most reviewers would agree that the primary source of information in assessing care must be the patient.

By now you will have gathered that IPR is viewed and has been viewed as a patient quality of care focus. That is its primary purpose and the purpose for which it was created.

While other useful results may come about because of IPR, the care given to the individual is its paramount focus. The Title XIX Statute calls for inspection by independent teams "of the care being provided in ICF's" as to "the adequacy of services available to meet the current health needs and promote the maximum well-being of patients." The necessity for, and desirability of continued placement, and the feasibility of meeting the patient's needs through alternative means are also tasks delineated in the law. These are all nice sounding words and phrases but what do they mean to you and your job?

Your responsibility simply stated is to see that the patients are getting the care they require in the setting most appropriate to meeting those needs. For the next few days we will be delving into various ways you can accomplish this heavy responsibility.

I'd like to turn now to some of the other results of IPR, both potential and actual. Before I do that

however, I'd like to say that the new Health Care Financing Administration, of which the Medicaid Bureau is a part, has stated clearly that it has a two-fold goal: to bring about containment of spiralling health care costs and to strive for quality health care for all of us. While these two goals are not necessarily impossible or incompatible, you can see that all of us involved in publicly financed health programs, Federal, State and local, have a difficult and delicate balance to strive for. I believe it can be done.

Keeping in mind the sensitive balance of health care cost containment and quality of care then, I'd like to mention some of the ways the reviews, PMR and IPR can accomplish the two goals.

I'd like to give you some examples that I think have achieved cost savings, improved quality of care and most important of all, added intrinsic and immeasurable social values by assuring patient individual rights and dignity.

These contributions were and are being made by review teams:

Patient advocacy. I am often told by reviewers that they frequently hear (and attempt to resolve) patient complaints that otherwise either would never have been voiced or would go unheeded.

Quality of Care. Reviewers have found conditions so miserable that all Medicaid patients were immediately transferred out of a facility.

Fraud and Abuse. Reviewers discovered and reported that a particular pharmacist was dispensing generic drugs to nursing home patients, but labeling the containers with brand names and billing for brand names. The State agency investigated both actions; the pharmacist is no longer a Medicaid provider in that State. Therefore, reviewers can and do assist a State in its fraud and abuse efforts.

Reviewers have discovered over-prescribing, under-prescribing, contra-indicated drugs, services billed but not delivered, and many more. Such discoveries can be cost-effective in both human and fiscal terms.

To address the potential benefits that could accrue from PMR/IPR, I'm going to first give you some facts about the Medicaid program. In FY 76, State and Federal funds amounting to \$5.2 billion dollars were spent for long term care - that was 38% of the total national Medicaid budget. That figure does not include payments for such services as physician visits, drugs, therapy, etc. for nursing home patients. Medicaid pays for 49% of the nursing home care in this country.

Nursing home care consumes from 35% to 55% of State Medicaid budgets. Care in ICF/MR's in 1976 cost approximately \$600 million with only 38 States participating. More States are coming in to the ICF/MR program and others expanding. Obviously, analysis, planning to meet the need and just plain prudent management of long term care resources are vital.

I would submit that much data that could be used for analysis, planning, and management of long term care programs is available because of the review effort. In fact, in those States that have computerized their review forms the capability already exists to use review data to determine many important factors upon which decisions and resource management can be based. For example:

- Data to project the need for adult day care, home health, etc. for the known population can be obtained based on the team's documentation of any patient's need for other non-institutional services. One reason States have not embarked further into day care, group homes, and so on is the lack of data to gauge the demand for such services. Thus, documentation of the patients' need for alternatives after placement in an institution is crucial and can be extremely useful to

planners.

- Need for careful assessment prior to institutionalization can give an even greater payoff.

In closing, I'd like to reemphasize an earlier point: we at the Federal level view the review teams' role as crucial, and believe that you can make a real difference in nursing home care. Your job is difficult but accomplishable and your impact on improving quality of care can be neither underestimated nor finitely measured, encompassing as it does, so many intangible human values. We hope this conference will reinforce not only my words, but your desire to do your job well.

Thank you

PANELS

ACTION AND REACTION PANELS ON THE IPR

Moderator: Larry Levinson

Action Panel: "HOW WE DO IT"

Actors:

Norma Kelvev, IPR Coordinator,
Rhode Island

Angus Wilson, MD, Utah

Nancy Searcey, RN, Nebraska

Elmer Pierre, MSW, Minnesota

Reaction Panel: "HOW WE VIEW IT"

Reactors:

Robert Decker, Administrator,
Idaho State School and
Hospital

E. Gene Patterson, National
Association for Retarded
Citizens, Texas

Charlene Seavey, Utilization
Control Supervisor DPW,
Minnesota

INTRODUCTION

Action/Reaction Panel

The dual panel format was used to present a variety of State practices in implementing the Independent Professional Review process and to explore the issues associated with this process. Four direct representatives of the IPR process (team members and coordinators) comprised the ACTION portion of the panel, and three representatives of groups impacted by the IPR process comprised the REACTION portion of the panel. Mr. Larry Levinson was Panel Moderator, and Mr. Matt Brown and Ms. Ginger Hale served as Federal resource persons.

Each ACTION panelist had approximately ten minutes in which to present highlights of the ICF/MR program and the IPR process in their respective States. REACTION panelists were invited to raise whatever issues seemed most relevant from their agency's perspective. Audience participation was encouraged.

This section includes a verbatim transcription of panelist presentations and portions of the subsequent discussion.

ACTION PANELIST

Norma Kelvey

Rhode Island has been conducting medical reviews in regular ICF's since 1974. Since the new requirements came out, we have also been doing reviews in ICF's/MR. The forms that we developed initially for the medical review in the ICF's, of course, had to be revised. But, we do use a similar format for doing the ICF/MR reviews in that our forms go to a computer for a print-out. The agency that we contract with for the computer wanted as similar a format as possible.

We have four forms--really five forms--that are used. Initially, we send a pre-review profile to the facility asking them to provide identification data for their residents. Until about a year-and-a-half ago, the pre-review form had a question on ADL scoring, but we found that when the review team went in, it was of no use to them because it was not accurately filled out. There were also questions on feeding, bathing, dressing, ambulation, assistance, etc. We now have a simple form that we send which just lists patients' names, past residence, relatives, level certified by SRS, marital status, sex, etc.

In addition to the pre-review form, we have forms which are color coded, for the social worker, the nurse and the QMRP. The first time we reviewed ICF's/MR, we

used a physician on the team. The second time around, we did not use a physician, but utilized the services of a qualified mental retardation specialist as a member of the team. We are now going on a third round into the ICF's/MR, and we have decided again to eliminate the physician from the team, and use a nurse, a social worker and a qualified mental retardation professional because of the resistance of physicians at our State operated MR facility to having so much emphasis on the medical aspects rather than social aspects. There was also reluctance of the physician on the review team to go back to the facility again. They felt it wasn't necessary because medical care was not the major problem at the facility and also that they were not that familiar with programs for the retarded. The program areas that were lacking were in activities, recreation, speech and physical therapy.

Some of the things the QMRP's are looking for are evidence in support of admission, including: social history; current life status; that a psychological evaluation by standard tests of observational procedures appropriate to the individual have been made; that alternative placement options were considered at the time of admission; that the facility has developed a habilitation plan based on assessment and it is adequate to the individual in terms of self-care skills, social

skills, communication skills and work skills; and where appropriate, the following services are provided: schools, sensory-motor training, speech and language therapy, psycho-therapy and chemo-therapy. Also, there is a question on whether the plan is reviewed and updated on the basis of continuing observation and assessment of the resident's needs.

We have three teams. They are employed by the Department of Health which bills the State Social and Rehabilitation Services for the time spent on IPR and Medical Review. The teams have the option of conducting the on-site visits as they wish, either looking at the records or the patient first. They prefer interviewing the patient first, taking notes, and then going to the records. This is how our teams have been doing it.

From what I gather, the social worker on the team does most of the interviewing. He has his own form that he needs to fill out. He also needs to go to the record to be sure that certain things are recorded. His interests are in the residents' relationship with the staff, relationships with other residents, the residents' attitude, family involvements, and what sorts of activities the resident participates in. All team members have a question on resident placement that they fill in on their respective forms. When the social worker goes to the record, he is looking to see that

the social needs have been identified, that goals have been established, that there is a discharge plan or reason for continued care, and relevant family history.

The nursing review form had to be severely modified from that used in medical review since the nurses are the ones who are looking at what the physician is doing when they review the medical record. They are looking to see that the medical diagnosis is there, that there is a medical treatment plan which has been reviewed and revised and what medications have been ordered. The nurse also looks at nursing care: what is needed by the patient, ambulation, speech and hearing, podiatry care, dental care, and so on and so forth--Is the patient clean, is the resident up-and-about, is the resident able to ambulate freely or with assistance? After the review, the team members then sit together for a conference and come up with a recommendation for future placement for the resident.

We have one large State institution in Rhode Island. It may not be large in comparison with other states because we are a small State, but in the IMR's we have a total of approximately 800 patients. At our last review there were 267 recommended changes. Of these, one resident was recommended for transfer to a psychiatric hospital, two residents were recommended to ICF II's, five to ICF I's, two to skilled nursing,

two to apartment living, and the rest to ICF/MR community residences. We have only five ICF/MR community residences, so that many of these patients, of course, are still in our State institution. However, we are expecting to move more residents to the community in the future. A bond issue was passed last November which will make it possible for the State to buy and lease community residences for the mentally retarded.

We do have a very active Association for Retarded Citizens in our State. Every city and town has centers for the retarded with workshops and educational opportunities in addition to what the schools offer. Most of our residents who are in community facilities actively participate in these community centers for the retarded. In this connection, we had problems in the beginning, in that the centers thought that the participants were their patients. All of the records were at the centers and the community residences had nothing. Practically all the community residences did was serve the residents breakfast and provide them with a place to sleep. It took a lot of teaching and a lot of convincing to persuade the facilities that they had to maintain a record with all necessary elements to get them certified as ICF's/MR.

All ICF's are visited semi-annually. Instead of

instituting a separate utilization review in the ICF's, it was decided last year that the IPR teams would visit facilities on a semi-annual basis. We have both pro and con feelings about going into the ICF's/MR semi-annually. The teams seem to feel that the changes in the patients simply do not warrant visits every six months. They feel that the patients' rate of change is slow and that semi-annual visits are too often for the MR's to be reviewed - and it is costly.

We have, as I said, a nurse, a social worker, and a QMRP, on our teams. The QMRP, at this time, serves on a consultant basis to us. However, we are interviewing at this time to hire a full-time QMRP to serve on our staff. All of our social workers on the teams do have their masters degrees, and one of them is qualified as a QMRP. However, he does not want to limit himself to ICF's/MR. He likes the variety of the skilled nursing facilities, the regular ICF's and the ICF's/MR.

It is interesting to note the ages of the residents in our state institutions. In the 0-5 range, we have 1 resident; ages 6-10, we have 6 residents; 11-15, 48 residents; 16-20, 85 residents; 21-30, 203 residents; 31-44, 142 residents; 45-64, 158 residents; 65 and over, 35 residents. In terms of length of stay in this institution, there are 10 residents who have been there

less than one year; 1-3 years, 45 residents; 4-10 years, 148 residents; 11-15 years, 116 residents; 16-20 years, 52 residents; and 304 residents have been there over 20 years. This, of course, does not compare to our community residences because they have been in existence for only a short time.

The first year we reviewed our community residences, there were five residents who were recommended for residential or apartment living, and two to a rest home. In the last review, there were no changes which were recommended by the review team.

In conclusion, as my time is running out, because the review teams do see each and every Medicaid resident and do a thorough record review, they have been able to assist the facilities in improving their care to the residents. During the exit interview, the team members are able to point out areas needing attention and point out problem areas.

ACTION PANELIST

Angus Wilson

My name is Angus K. Wilson, program head for Utilization Review in the State of Utah. We operate within the Bureau of Medical Review Services, which is within the Utah State Division of Health, under an agreement with the Office of Medical Services, Department of Social Services.

Our mentally retarded population in Utah is 1200 who are distributed over nine facilities. The largest of these is the Utah State Training School which has 840 residents--all of whom are mentally retarded. That population is down from the previous total of something over 1100, due to increasing placement in other facilities, and also because more retarded are in work-supervised, cottage-type homes which provide housing and meals. The next largest facility is the Clearfield Training Center which has 103 mentally retarded residents, and that also is made up of 100% mentally retarded. The other facilities range from 50% to 95% mentally retarded. In addition, there are ten private nursing homes for which we have no break-outs of the number of mentally retarded. The total number of beds in those nursing homes is 300. The percentage of mentally retarded patients in the Medicaid program in Utah is 20.5% of the total Medicaid

population of 5845.

On the last six pages of the manual you can see the draft Utah form which our teams complete during their visits to facilities. I might mention that the form was changed--just three days before I left. The first two pages are still intact, and we will continue to use those, but the remaining four pages have been drastically changed. If you are interested in receiving the most recent form, I suggest that you take down this name: John D. Hunter, Coordinator, Utilization Review, 44 Medical Drive, Salt Lake City, Utah, 84113. The revised forms have not been printed yet. They will shortly however, and if you will request the form, I'm sure he will be glad to give you a copy of it.

Our teams are composed of a nurse and a recorder. When they visit a facility they make out their own face sheet. The recorder assembles information and gets the pertinent information regarding the identification of the patients. The recorder also digs through the chart to find the medical diagnosis and fills in the information regarding medications. I think this is a weakness in that medical recorders are not skilled in getting all the information from the charts regarding diagnosis. I find that I still have to go through the nurses' notes quite frequently,

and also into the lab studies to find out, for example, why a patient is getting thyroid when there is no diagnosis of hypothyroid on the chart, but it does show up in the thyroid profile.

The nurse sits down with whoever is knowledgeable regarding the patients, usually the LPN in the ICF facility, and gets the information regarding patient characteristics, the nursing requirements and all the rest of it. Following the interview with the care staff and the assembly of information from the record, the nurse--accompanied by the recorder--goes around to observe and interview, where its feasible, each of the patients in the facility. We have a social worker, of course, but unfortunately the social worker's sheet is not included in the draft form. It will be included in the final form when it comes out.

My own particular role in the IPR process is not too involved. After the review is completed by the nurse and recorder, I review the charts they bring in and try to form an idea as to whether or not those patients are in the proper level of care that they need. One of my functions also is to code the diagnosis so that it can be put into the computer and used for future reference, if need be.

The ICF's are reviewed annually. The skilled nursing homes are done semi-annually. The approximate

per-resident time for the review is twenty-six minutes. We did a program study in 1971-72 in which we were required to show the length of time for each facet of our activities: the time for travel to a facility, time spent observing and/or interviewing the patient, the length of time it took the recorder to get the information, and the length of time the physician worked on the records. All of those things were recorded and we found that in the IPR program, which was one part of our project, it took twenty-six minutes for the nurse and the recorder to get the information they needed.

The order of procedure is to call the nursing home, generally a little over forty-eight hours before we do the review, except in the outlying areas--some 200-250 miles away from our headquarters. In this case, it is not always feasible to give them forty-eight hours notice because the nurse may be on vacation or have other involvements. So, for the more distant facilities, we give a little more than forty-eight hours notification.

We have not run into any resistance on the part of the nursing homes, at least not since the first six months, when we had some problems. However, more recently, we have been operating very smoothly and we have had excellent cooperation from the nursing homes.

So far as physician coverage in the institutions is concerned, we don't have any real major problems. The doctors are very good in Utah--they have become educated. Some resist going in every sixty days to see the patients, but the nursing homes now are gradually getting a staff or house physician, and that has alleviated the problem of physician visits to a great extent.

My principal objection to the IPR process is that, while the nurse and recorder can observe and interview the patient, the physician is denied the privilege.* You can get a great deal of information from looking at the patient and checking this against the records to see what those patients look like and how they are getting along, and if they are getting the kind of care that they need. Also, as I mentioned before, recorders are not skilled, unless they have very special training, in digging through the charts and records and getting all the medical information that should be assembled for a good evaluation of level of care. Except for these two problems, I think that the program works quite well.

*It was subsequently pointed out that this was a State variation. Federal regulations do not prohibit direct physician contact with ICF/MR residents.

REACTION PANELIST

Robert Decker

I have a few reactions. First, as a facility administrator, I think that it's crucially important that the IPR team members, including the physician, be able to have direct access to the patient during the review process. They need to be out there viewing the patient to see that the care is given. That's what the IPR is all about.

Secondly, I have some strong concerns about the IPR teams engaging in patient assessments on the basis of a 25 minute evaluation and then using those assessments to determine what's appropriate and what's inappropriate programming for an individual.

I don't see why we should have new kinds of criteria for IPR teams to evaluate patients on and I object to the Manual's suggestion that we should. I think the criteria should be laid out in the individualized treatment plan and that the IPR team should look at whether the patient is benefiting from that plan. As an administrator, the last thing that I want to see is a new set of criteria developed which I am going to have to meet--because you're going to put me in the position of just running around meeting criteria, and never addressing

individualized patient needs. I think that it is wrong, personally, for the IPR to engage in patient assessments. I think that it's great for them to look at the patient, to look at the treatment plan, to see if the patient is progressing and benefiting from those plans, and then to determine whether or not the patient is appropriately placed in that ICF facility. But, to go in to try to do patient assessments on the basis of quick evaluations is not sufficient. Further, as we have already heard once today, IPR staff frequently do not have sufficient expertise to conduct patient assessments--as compared with the facility. In my facility, I have got several Ph.D. psychologists who have spent an extensive number of years in training on MR; physicians who are used to dealing with them; special educators, and it goes on and on--OT, PT, etc. These are the people who prepare the treatment plan. And now you are going to bring a nurse, social worker, and QMRP into my facility who are going to tell us that it's all wrong.

I don't think you have the guns to tell us that the treatment program is not correct. I do think you have the capability of determining whether or not the services are being delivered. Example: If it is said that a resident can button his shirt, you can

say, "I'd like to see the resident button his shirt." I think you can do that, but frequently I don't think you've got the time, the manpower or the expertise to write up treatment programs and do complete patient assessments--particularly in rural States, where the teams are reviewing both SNF's and ICF's as well as ICF's/MR.

Comment from audience:

I think we do need criteria, and the less expertise on the team, the more the need for written criteria. Without criteria, the teams are reacting subjectively.

Robert Decker:

I think you do have criteria--they are spelled out in 249.13. I think that, in fact, you should be monitoring not only the plan of care and whether or not that's written but you need to monitor and determine whether or not the evaluations have all been done by the various people, what the recommendations were out of that and also the residents' progress towards that plan of care. I think if the resident is progressing in that plan of care, and there is significant progress, then he's probably

receiving an appropriate program. I think if he's not making any progress in a facility, that's when you would begin to question the appropriateness of that individual's placement, treatment plan, evaluation, diagnosis and the whole picture.

Matt Brown (Federal resource person)

I'd like to comment on what I've heard from the previous speakers. First, the regulations do not preclude a physician from being on the team and going in to take a look at the individual residents. The physician may be excluded from seeing the resident in a particular State, but the regulations certainly do not prohibit the physician's contact with the residents.

Secondly, I think 250.24 specifically requires that one of the main functions of the IPR team is to make a determination concerning whether the resident is getting the kind of quality care he deserves, which includes an assessment of the individual's plan of care. We recognize that the interdisciplinary team has the responsibility of developing plans of care, but it may not have been developed to the extent that it's fully meeting the resident's needs. One of the requirements of 250.24 states that the IPR team will make a determination as to whether continued residential or institutional care is recommended for this individual. The team is also to make a determination as to whether this individual is appropriately placed. Now...if you're simply going to assess whether the individual is making some progress (even in an ICF general...he's likely to be making progress), then

you're saying he's appropriately placed in this particular institution, although he may be able to benefit from a more sophisticated treatment program in an ICF/MR. The task, then, is not to determine whether he's making progress (because if you're getting nothing, even a little bit is progress)--but, whether this placement is appropriate for him or whether he'd benefit from an ICF/MR program. What I'm saying, really, is that we are not going to let anyone circumvent the requirements of the ICF/MR regulations by saying "well, we are doing the best we can for the individual." Therefore, a complete assessment of this resident is essential for the IPR team. And, you will recall, that the regulations require that the team prepare a report to include recommendations--which means that after the review is completed, the team is to submit a report of its findings and recommendations to the single State agency and circulate the report to all other appropriate agencies.

As stated by Mr. Hyde and by Mr. Silva this morning, we certainly are going to be interested in the quality of care received by the individual. This is one of the primary functions of the IPR team--to ensure that individuals are getting the kind of service they are entitled to. And it must be the IPR

team who is going to determine whether this individual is getting quality care, whether he is suited for an institutional placement, or whether he should be in another setting altogether. The survey team will certainly certify the fact that a facility has the capability of providing appropriate care. But, we must depend on the IPR team to determine whether the care the individual is getting is adequate.

ACTION PANELIST

Nancy Searcey

Hopefully, my remarks won't be too disjointed.

I am a long-term care supervisor in the Department of Public Welfare in Nebraska. We have a total of about 8200 Medicaid recipients in approximately 220 facilities. This includes all levels of care. Breaking out the ICF/MR beds, we have 994 that are in State institutions. We have two non-profit ICF/MR facilities that are totally certified ICF's/MR with a total of 384 beds. We have two proprietary ICF's/MR--one is a totally certified ICF/MR and the other is a dual certified ICF and ICF/MR. We have an additional four or five proprietary homes in the State that are in the process of certification for ICF/MR.

Our State is broken into six regions. We have review teams in each of the six regions operating out of regional offices. The teams consist of one medical social worker, and from one to three regional field nurses.

About a year-and-a-half ago, through the process of medical review and IPR, we began trying to identify all ICF residents with a diagnosis of mental retardation, in order to determine whether their placement was appropriate or not. We have requested that each identified recipient in a facility have an independent

programmatic evaluation to try to determine whether they are receiving the necessary services. As I said, this was done about a year-and-a-half ago. We are now going around the second time, trying to evaluate this information which has been obtained by the facilities, in order to assess whether the residents are appropriate in an ICF or should they be alternatively placed in an ICF/MR, or into community-based placement. It has been a slow process, but we have seen some good things happen. Hopefully, as we develop more alternatives to ICF care for those who have been determined inappropriately placed, we'll have the services for the recipients as they are needed.

We have used our review teams to conduct both medical and independent professional reviews in all types of facilities. We do have to supplement these teams with personnel out of the State office. We are just beginning to get into the program of IPR in ICF's/MR. We are hoping to develop a review team specifically for ICF's/MR, to work out of the State office. Basically, all of our facilities are in the eastern third of the State within travel distance of the State office. We feel that we would like to develop a specialized team to work in the ICF's/MR.

At this point, we are using the survey forms

that were developed for the review of regular ICF's.
We are now in the process of revising our forms and
our manual material.

That's a brief overview of what's happening in
Nebraska.

ACTION PANELIST

Elmer L. Pierre

I've had experience in working with MR people and their families in a Community Mental Health Center, a County Welfare Agency and a private-for-profit set of treatment group homes. My experience involved direct treatment and consultation with individuals, families, sheltered workshops, schools, day activity centers, and courts.

STATEWIDE PROFILE OF MEDICAID RECIPIENTS LABELED M.R.

A. Population

There are 6,330 MR recipients. Seventy-seven (77) percent or 4,868 are in ICF/MR licensed facilities. One thousand, four hundred and sixty-two (1,462) are otherwise placed.

B. Nature and Number of ICF/MR Facilities

Table I

1975	Facilities		Beds	
	#	% of Total	#	% of Total
Residential (< 16 residents)	63	56	641	10
Large Community (> 15 residents)	41	36	2078	32
State Hospital	9	8	3781	58

C. Trends and Problems

1. The "Deinstitutionalization" Trend

The State Hospital MI and MR population in Minnesota in 1960 was 15,194, in 1965 was 11,576 and by 1975 had shrunk to 5,496.

There are still 2,925 MR citizens in State Institutions, most of these are categorized as severely or profoundly retarded.

Table II
Licensed Placement, MR Citizens,
Minnesota

Facility	# of MR's	%
SNF	432	7
ICF I	794	13
ICF II	197	3
Resident (< 15) ICF/MR	484	8
Resident (> 15) ICF/MR	1459	23
State ICF/MR Institutions	2925	46
State Psychiatric Hospitals	39	1

2. The Smaller Residence Trend

The last three years have seen a rush to

ICF/MR residences with populations of 1500 or less. Frequently, there are no more than six in family-style group homes.

The 1976 total of these facilities was 101, a 60% increase over 1975.

3. The Difficult Placement Problem

The rapid emptying of State institutions was in part facilitated by the higher functioning nature of the first and second waves of discharges.

We now are faced with finding community placement and acceptance for the more difficult segments of the MR population.

D. The IPR Process

1. IPR is done by the Quality Assurance and Review Program. We are a part of the Minnesota Department of Health. Our function is single purpose. Licensing, Certification, Technical Consultation and Training are done by two other programs in the Department of Health.

All of these are answerable to our single State agency, the Department of Public Welfare.

2. The State is divided into eight geographic regions. There are eleven IPR teams comprised of an RN, a social worker and consulting physician.

There are four teams assigned to our Metro area (Minneapolis-St. Paul). This is sometimes

referred to as "the Seven County Mosquito Control District," or this year, "the Dutch Elm Disease Removal Area..." Germans, as we all know, bear no ill will toward Elms! Thank you for bearing with me as I schized off...okay now I've found my place.

Our IPR teams review SNF's, ICF's and ICF's/MR.

3. We review each facility once a year. We spend approximately twenty to thirty minutes per resident.

4. Our review sequences look like this:

The initial facility letter is sent six to eight weeks prior to the scheduled reviews.

The package includes a blank form for each resident and an instruction booklet to guide the facility in filling out the first pages of the form.

A copy of our form is Appendix A in the back of our program's sample draft manual.

Note that we ask the facility to fill out the first page. Our rationale for so doing is that we hope to teach what constitutes a complete medical and psychological record.

Note too that on Part III, page 1 of the form, we validate and record in Column 2 our findings in the record for comparisons.

Forty-eight hours before the scheduled review, the facility receives another letter apprising them of which team will be coming.

The day before the review, a team member phones the administrator to set up an entrance interview time.

The review itself follows this sequence:

1. record review, 2. resident interviews,
3. staff interviews and 4. recommendations (if any) on page three of the form.

Then, the exit interview is held with the administrator and anyone he/she designates to sit in.

The team goes over the form and summarizes the recommendations.

The forms are processed in the office. Copies of each individual form and a cover letter are sent to the facilities' Utilization Review Committee.

The letter includes recommendations for level of care changes and study topics.

Study topics are selected by weighing the incidence of recommendations in the various areas.

The UR Committee must respond. They may agree or disagree but they must respond in writing to our recommendations.

A word here about our teams and their review process. Our emphasis is on outcome and not process. We emphasize that we are interested in the results of care, not how the care is delivered.

While treatment modalities vary, the welfare of the individual is the important constant.

5. My role in the review process may prove interesting.

The majority of our eleven teams work as independent and consultative individuals. The nurse and social worker review the residents' care totally. We are responsible for total resident review.

That is, I do the chart, resident and staff reviews (and interviews) on all aspects of care.

When social workers have questions about nursing care on their case reviews, they consult the nurse. When nurses have questions about psycho-social problems in their individual reviews, they consult the social worker. When medical questions appear, the consulting physician is consulted for a medical opinion.

As far as the make-up of the teams in Minnesota, I might point out that the nurses, as previously mentioned, are RN's. The social workers are mostly Bachelor-degreed people. At least one has

a graduate degree in a related field. I'm the only M.S.W. at this time.

I'm their token M.S.W. After all, the State of Minnesota is an equal opportunity employer!

REACTION PANELIST

E. Gene Patterson

Since you are well qualified and experienced in assessing health-related issues, I will limit my remarks to some of the special developmental concerns we have for developmentally disabled persons.

I would like to draw your attention to NARC's Position Statements on Residential Services. In addition to the variety of problem issues and specific organizational positions, thirteen basic principles are enunciated which serve to assess the question of appropriate services. These statements will be helpful toward your understanding of NARC's advocacy position and to your understanding of some controversial aspects of residential service approaches. You may secure copies by writing to NARC's Publications Department or to your State Association for Retarded Citizens.

As a consumer advocate, NARC has specific and profound concerns about the evolution of residential service systems for mentally retarded and other developmentally disabled persons. We are concerned about abuses in residential facilities; not just the gross physical abuses, but also the more subtle and sometimes occult abuses. People with developmental disabilities are especially vulnerable to a variety of abuses associated with decreased and limited oppor-

tunities.

As you think about your own roles in the certification and review process, think about this issue of "opportunities for development." There are four consistent questions you should ask and probe in every facility.

Mobility. What is being done to help residents increase their ability to move about within their environment? There is abundant evidence that people who are restricted to bed or confined in limited spaces suffer both physical and mental deterioration. That hardly seems consistent with a mandate for "active habilitation." Yet, one is often surprised to find individual habilitation plans prepared for multiply handicapped individuals, which proceed with an assumption that mobility is either irrelevant or impossible.

To the developmentalist, that constitutes abuse.

Meaningful Activity. How does the client/resident/student spend his or her day? It is easy to spot the programs which impose idleness and apathy as a lifestyle, but it may take a sharper eye to discern that a busy day filled with meaningless activity is simply another form of ennui. The purpose of an individual program plan is to assure that program activities meet the individual's developmental and habilitation needs.

All of you may not have the program experience to assess the quality of sophisticated program plans, but you can all certainly distinguish meaningless activity.

Decision-making Opportunities. How does the program provide for client/resident participation in making decisions? People who have few, if any, opportunities to make personal decisions relevant to their lives, are "wiped-out" people. They are, in reality, prisoners of external controls. People who view themselves as totally controlled develop destructive and deteriorative self-concepts. They feel powerless, helpless, irresponsible, useless and only marginally human. Those who challenge the controller or attempt to exercise personal preference are frequently labeled "uncooperative," "stubborn," "obstinate," "resistive," "negative," "hostile," and probably "dangerous." As you know, those people often have standing orders for chemical and mechanical restraints, which brings us to the fourth question.

Medications. What is the rationale for use of psychoactive drugs, and what safeguards are employed? The continued widespread use of psychotropic drugs represents a special concern. While not wanting to overlook the value of wisely prescribed medications, you are apt to find many abuses in the use of some drugs. For example, the use of phenothiazine derivatives

such as thorazine, mellaril, stelazine and sparine are probably contraindicated in the presence of mental retardation. These drugs interfere with perception and depress sensory input. They are, therefore, likely to impede learning and hamper development.

Bob Decker has suggested that "the IPR team's role is not to assess the treatment plan, but to assess whether or not the patient is benefiting from the plan." We would agree that the average IPR team may not be able to fully assess the plan, but we expect the IPR team to have sufficient knowledge to identify whether or not a resident client's gross needs are being met and whether there is planning directed toward the client's continued development. In my opinion, the IPR team does have a responsibility to assess program priorities. If a facility cannot meet the client's program needs, either directly or through contracted services, then the facility should not have accepted that client in the first place. National accreditation standards and Title XIX regulations both seem clear and straightforward on this issue.

There is a curious assumption within the field of human services that a direct relationship exists between program costs and program quality. Beyond a reasonable relationship this is a false assumption. Staff ratios and program expectations are especially

vulnerable to this faulty assumption. The research literature on direct care staff is woefully inadequate and confused, but it does support the conclusion that increasing staff ratios does not necessarily result in better programs. The literature also supports a notion that the critical variable in program success is the quality of interactions between client and staff. Therefore, give this interaction your careful and expert attention--it will be a most useful observation in the overall assessment of a facility's program services.

It is the quality of programs which will, in the long run, determine the future of Title XIX services. When we consider the rapidly expanding costs of these programs, we have a legitimate concern for the future. Gene Hyde noted that the program costs grew to \$600 million in 1976, and it has been conservatively estimated that the program will exceed \$1 billion by 1980. Even though the Medicaid program is thought of as open-ended, we can be pretty sure of a Congressional review as a result of this rapid expansion. The likelihood of cutbacks is a reality we cannot ignore. There is little evidence that States are planning for this potential disaster. If his program is terminated, there is no place for the ICF/MR resident to go except back to the institutional setting which consequently

will be overcrowded, understaffed and underfinanced again. That is a particularly disquieting thought!

However, if the ICF programs are really meeting the service needs, the dangers of severe funding cuts are reduced. In many ways you, as members of the IPR teams, will influence that future. You have the questionable honor of being responsible for what the ICF/MR will become--it is dependent upon how much you can shape the service system via implementation of State and Federal regulations. It is an awesome responsibility, and you have our admiration and our offer to be of assistance in whatever way seems most appropriate.

REACTION PANELIST

Charlene Seavey

As a program administrator representing the single State agency, I have to be concerned not only with the Independent Professional Review (IPR) for mentally retarded, but all elements that constitute utilization control. One of the primary concerns is the money angle; that is, are we getting what we are paying for. In Minnesota, we have seen a fairly good success ratio in facility responses to the recommendations made by the Periodic Medical Review (PMR) and IPR teams. In IPR for the ICF's/MR, we have had some added incentives in that there is strong backing in the form of program rule (our DPW-Rule 34), legislation, education, general community support, and a commitment by both the Department of Public Welfare and the Department of Health to have individuals appropriately placed. I might mention that Minnesota has about 170 community-based ICF's/MR ranging in size from six to over a hundred beds, plus a State Hospital system that has 3,600 beds. Minnesota has been developing its community-based ICF/MR concept since the early 1970's; therefore, our State Hospital population is already down. Are ICF's/MR expensive? Yes, but we have seen success stories of individuals moving from State Hospitals to community-based ICF's/MR

to independent living situations so we do not consider it a waste to go this route.

I think we all have to look at the total review process; in particular, the number of reviews required by the utilization control regulations in 45 CFR 250.18. For ICF's, reviews are required prior to admission by an interdisciplinary team, then physician certification, physician recertification every sixty days, review of the plan of care at least every ninety days, utilization review every six months and at least an annual IPR. I'm not saying that each review in and of itself does not have merit, but rather, how many times and how much money can we afford to spend to ask the same basic question, "Does this person need to be at this level of care?" In all instances, it is impossible to get at the answer to a very subjective question, "Is this person getting the care he or she needs?" As far as reviews go, I think Minnesota's PMR/IPR process gets the closest to answering this question.

I do not agree that increasing the number of reviews enhances that unknown entity known as quality of care, and that cost containment is therefore achieved. I think we are only kidding ourselves, when we are talking about cost containment, if we do not take a look at all the utilization control require-

ments and, in particular, who is designated as having the control. The individual specified throughout most of the review processes is the physician. It makes for a terrific medical model, which does little for me when we are talking about long term care. The model does not fit for ICF/MR, and does little for general ICF and about 80% of the SNF.

To narrow down cost containment a little more, consider the psychological evaluation three months prior to admission to an ICF/MR contained in 45 CFR 250.24. To the best of my knowledge, this is the only reference made to such a time period in all the regulations. Administrators in ICF's/MR are shocked when they hear that an evaluation has to be done three months prior to admission and scream about the waste of money. On the latter, I couldn't be more in agreement. Therefore, why do we have such a regulation? The only rationale I can come up with is that we have to make sure the person is truly retarded. I do not know about other States, but our community-based facilities do not admit children until they are at least six years old. A younger child could be found in our State Hospitals or in a foster home if not in the parental home. The point is that tests are performed prior to any institutionalization - some for quite a few years. Why, then, is it necessary to go

through another evaluation just prior to admission to an ICF/MR? This is an area where trying to effect appropriate placement not only becomes nonsensical, but extremely costly. It also has the regulatory requirement inappropriately placed in a review process instead of as a program expectation.

Another prime objective of all reviews is to promote the most effective and appropriate use of available services and facilities for eligible individuals. In this, we are, by inference, to seek out alternate settings for people. On the surface this sounds terrific until someone asks who will pay for a setting outside of "medical setting." The answer comes back SSI and a supplemental money program. Does this really then become a viable alternative? Certainly it decreases the Medical Assistance dollar, but does it really decrease the taxpayer dollar? Yes, if only one source is considered. But, I doubt it if all the costs of maintaining the respective staffs for determining eligibility, sending out checks, plus Medical Assistance, etc. are considered. I think we have to think about taking money out of one pocket and putting it into another pocket - the Peter paying Paul concept. What it comes down to is that it's all tax money; therefore, it should be used in the best way possible to provide for the needs of

people.

To sum up my concern, it is frustration about duplication of review processes, lack of cost effectiveness, lack of uniformity with facility regulations, but, most of all, how is all of this benefiting our recipients and are they actually receiving the care they need?

LUNCHEON ADDRESS

"Evolution or Revolution?"

FRED KRAUSE

Executive Director
President's Committee on Mental Retardation

"EVOLUTION OR REVOLUTION?"

Fred Krause

There no longer seems to be much resistance to the idea that we made a mistake back in 1850 or so, when we created large public institutions to house mentally retarded persons.

I would contend that we still haven't corrected what has become a major social problem because of the age-old social practice of rejecting mentally retarded persons. Not just by putting them out of the way in big buildings, but for decades partitioning them off wherever they were.

We have all heard the expression that we must continue our persistence in seeking "mainstream living quarters for them" or how "traditional approaches" should be rejected. But I would like to add a few more items which may or may not be part of the scientifically designed accreditation or certification system you are-- or will be--using.

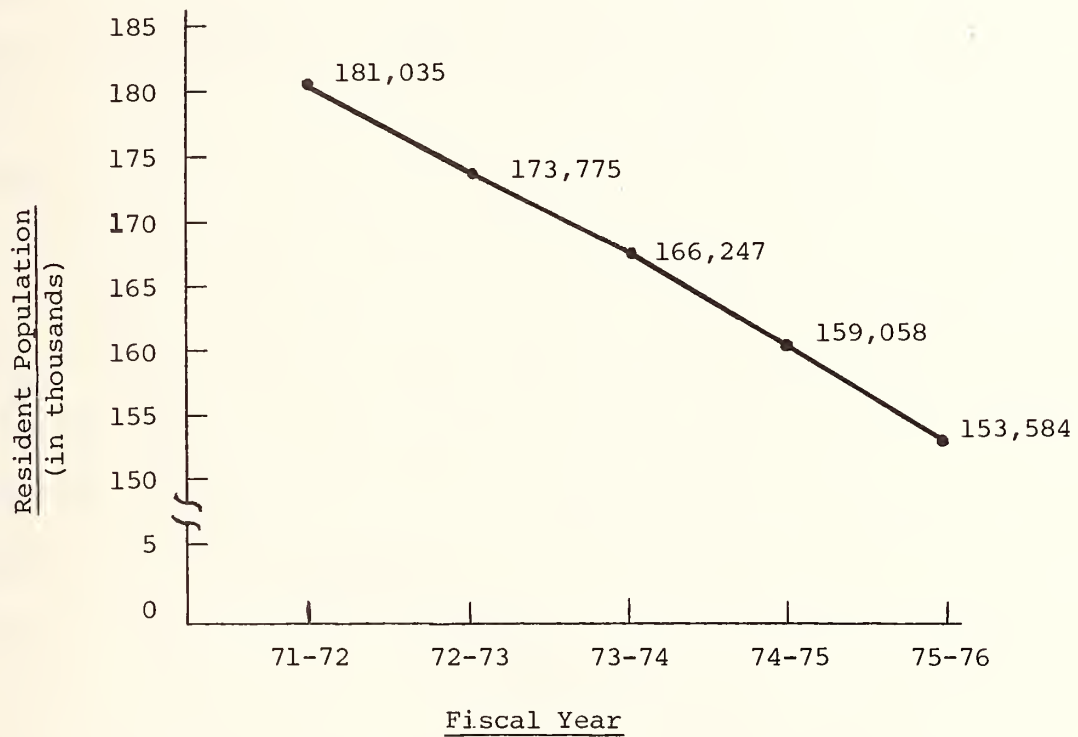
I would like us to keep in the back of our minds such things as "are we doing what we would like to think we are doing for mentally retarded citizens?" Whose problems are we solving when we move retarded persons out of structures we abhor into structures we prefer? Are we fair in our abhorrence? Are we rational in our

preference? Do the people who are being relocated share our feelings? These may be dismissed as an emotional plea having nothing to do with scientific discipline or even the discipline of work. So, instead, I would like to view these things as being intuitive or sensitive--both qualities being found in the best disciplined scientists or professionals.

I propose that you must be very mindful of the critical issues and management problems in the endeavor you are espousing. Years of study, lifetimes of professional effort have produced only partial solutions to the problems surrounding institutionalization and alternatives to it.

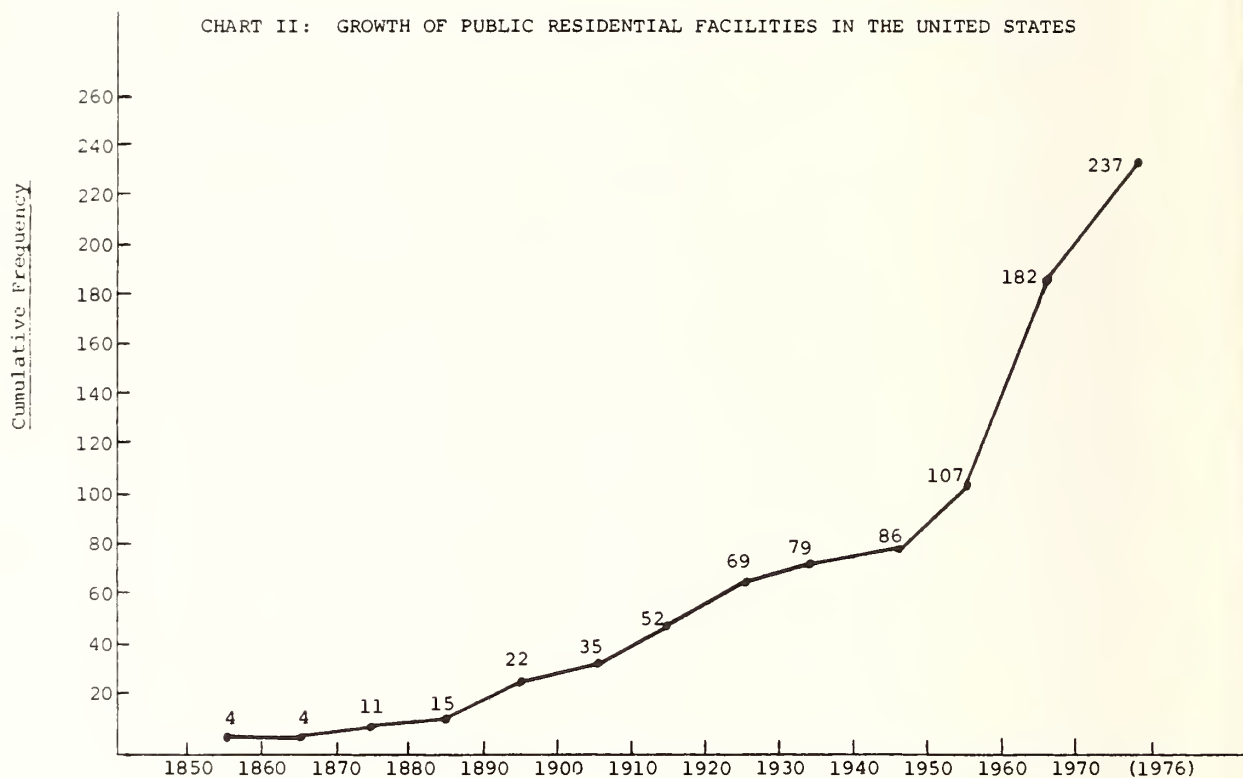
In 1971, a national goal was announced by the President's Committee on Mental Retardation (PCMR) to reduce the MR population by at least 1/3 by 1980. In 1972, this population was 181,035, in 1976 it is reported to be 153,584, a reduction of 20,351, or 16 percent (see Chart I). Dr. Richard Sheerenberger was commissioned by PCMR to survey the trends in public residential facilities. The following are the results of the study (Chart II). There are 237 operational facilities for the mentally retarded. Twenty-one (8.9%) opened between 1850 and 1899, and another 64 (27.0%) accepted their first resident between 1900 and 1949. Thus, the majority of public residential facilities (PRF's) have been established over the

CHART I



AVERAGE DAILY POPULATION OF 237 PRF'S:
FY 71-72 THROUGH FY 75-76

CHART II: GROWTH OF PUBLIC RESIDENTIAL FACILITIES IN THE UNITED STATES



past 26 years. Scheerenberger's data indicate that while progress is evident in both deinstitutionalization and institutional reform, much remains to be accomplished.

With regard to deinstitutionalization, the number of retarded persons requiring residential services continues to decrease, but at a slower rate than in former years. Other positive indicators include a reduced admission and readmission rate plus increased projected placement statistics for the forthcoming year.

While the resident population continues a gradual trend toward becoming both older and more seriously affected, many less affected persons (moderately retarded to normal) are still being served. Admission, readmission and waiting list data also include a relatively high percentage of moderately and mildly retarded persons of all ages. Too many individuals returned to the community appear to be failing because of inadequate local services. Taken collectively, these data clearly suggest that comprehensive community programs still need to be developed in many places throughout the country. The presence or lack of such community programs perhaps might be another "sensitive" point of awareness for those who are engaged in the work of certification.

Residential reform was evident. This was reflected in the general reduction in rated bed capacity, better

staff-resident ratios, increased enrollment of the severely and profoundly retarded in various programs, extended programming for adults, increased parental participation, and individual resident plans.

On the less positive side, and in spite of increased staffing and programming, very few PRF's can satisfy either the 249.12 or 249.13 standards associated with Title XIX, and relatively few have been accredited by the Joint Commission on Accreditation of Hospitals. Continued deficits in resident programming, the apparent need for special services for the emotionally disturbed, and the relatively high percentage of retarded persons maintained in locked wards during the day all indicate that substantial residential reform is still required. Also, the relatively common practice of retaining retarded persons in PRF's after they are capable of leaving needs to be re-examined.

As indicated previously, gradual gains are being made with respect to both deinstitutionalization and residential reform. Government, both State and Federal, has increased substantially their respective contributions to meeting the needs of mentally retarded citizens. A continuation of this concern and effort will be required before each retarded person can live a self-fulfilling life in the least restrictive environment.

Those of us in government service for mentally retarded persons--and PCMR in particular--are aware of this continuing need. But maybe I should write myself a little note at this point to make sure we continue to try to do something about it.

Can a community residence become an institution?

An architect who has designed many facilities for retarded persons says a community residential project often becomes an ego trip for the people involved (Sokoloff). He points out that "creating a building is a very intoxicating experience, for the result is a tangible and lasting expression of creativity." He also points out that buildings frequently fail in their purpose. In the words of another long-time observer, "anyone who has spent time in visiting new community establishments will have recognized with something like a feeling of terror that the abuses of the old system can be reproduced exactly and perhaps even more cruelly in the relative isolation of a community setting" (Shearer).

Attention is wrongly focused on the size and location of buildings in which retarded persons live. What matters more is the relationship between the provider and the client.

Don't kid yourselves. When a community residence is set up for retarded persons, it may be an institution

that is being created. It may be called a home, and it may be regarded as such by the people who live there. But it may be managed as an institution. Group homes, supervised apartments, and even foster homes employ labor, purchase goods and services, apply for and receive program funds. And a growing number of cases are mismanaged and lack individualized plans for their residents.

Like health care institutions, community residences have staffing problems. Low salaries, long hours, and lack of privacy--especially for live-in personnel--are facts you cannot eradicate, though there are ways of compensating for them. Personnel need emotional and educational support, as well as outside assistance from volunteers and paid workers.

Economic problems

Self-sustaining solvency is more likely to be a goal than a reality in a community residence for retarded persons. If they plan to pay for all the necessary services, they probably are headed for trouble. Jean Vanier, founder of The Ark (L'Arche), a frequently cited example of what can be done, states flatly, "our houses can only live through gratuity. If tomorrow everybody went on standard rates for hours and salaries, our houses would collapse."

Even under the best of circumstances it is unlikely

that retarded persons will be able to contribute much to their own upkeep by working. It has been found that jobs simply are not available. Many retarded persons now living in community facilities could work and want to work but cannot find employment. And when they do find openings, the wages are low.

Government support of retarded children and adults presently is too whimsical to be very helpful. Inequities and absurdities abound. A retarded person entitled to support in an institution may get nothing if he or she moves into the surrounding community. It is as though persons with mental handicaps are expected to earn government support by "playing dead" behind far-away walls. If they move into your neighborhood or mine, live in a house, and go to work, they are on their own.

These economic disincentives are irrational and unintentional, but they have not yet been dismantled. And we are on thin ice if we argue that it is cheaper to keep retarded persons in community facilities than in big State institutions. In the first place, sometimes it is not cheaper. Better perhaps, but not cheaper dollar for dollar. In the second place, it is hard to tell exactly how much it costs to keep people in institutions. Federal payments for institutionalization sometimes go into a general fund at the State

level and are spread around so that it is impossible to be sure money intended for retarded persons actually is spent to support the so-called beneficiaries.

Everyone would like to believe that community placement of the retarded is a sound business proposition, that community residences can be self-supporting, that goods and services can be purchased without reliance on cumbersome public funding and meddlesome bureaucracies. This is not currently a reality.

Once a retarded person is "released" from a public institution and placed in a less structured setting, lines of responsibility blur. Who ultimately is responsible for providing needed services? The institution? The community? The retarded person's family? When the crunch comes, who decides whether or not community placement is feasible, whether or not a specific individual should be sent back to an institution?

Community resistance

Receptive communities are hard to find. Group residences for the retarded usually are tax-exempt, and neighbors may fear erosion of the community tax base will result in higher taxes and fewer services. Unfortunately, areas that make it easy to establish residences for disabled persons may experience an unsettling influx of facilities. For example, in

Montgomery County, Maryland, where I live, a liberal policy on establishment of group homes for retarded people is in danger because neighboring counties and cities have taken advantage of the lack of necessity for zoning exceptions. Group homes are springing up all over, and the citizens are beginning to worry. The County Council is now considering legislation to make group homes get zoning exceptions before opening in residential areas.

Aside from economic considerations, it cannot be denied and must not be forgotten that many people are subliminally afraid of the handicapped. When these people say they are worried about property values in the neighborhood or the tax base in the community, what they mean is they fear mental deficiency, they are repulsed by disability, they feel threatened by the proximity of retarded persons. All of us must exert ourselves to counteract this sort of prejudice. Whose home is it to be?

A lot has been written and said about admissions standards for community residences, but there are few useable criteria. We must develop mental and physical function scales that are reasonably accurate in forecasting ease or difficulty of adjustment to community living. These predictive tools are necessary to plan supportive services. They need not become levers for

exclusion of certain retarded people.

Too often community residence planners gloss over the need to decide specifically and carefully what type of person will be living in the facility everyone is dreaming about. In committee meetings people tend to assume that the residence they are discussing will be inhabited by persons who are fairly mildly disabled, capable at least in some ways. Everyone knows some retarded people are much more handicapped than others. But no one wants to tell Mr. and Mrs. Smith, both of whom have been active on the committee, that possibly their child is too disabled to be managable.

When the really tough problems are mentioned--for example, physical impairment and severe behavior problems such as head-banging, violent emotional outbursts, biting, and sexual acting out--the planners say...well, this home won't be for that kind of person. Often no one is too clear on exactly who will live there, so the unspoken assumption prevails. The facility is built for "medium" cases, and when the slightly handicapped cream of the crop has come and gone, nothing can be done to accommodate more severely disabled human beings.

The good things about community placement

It has been shown that community placement does accomplish many of the things its supporters say it

will (Scheerenberger). A recent study of foster homes, group homes, and other community facilities for the retarded showed the people living in them did indeed prefer the community to the institutions they had left behind. Even the more severely retarded and multiply handicapped were adjusting well. Even the older adults were showing measurable progress toward independence.

But some problems were obvious. Foremost, work opportunities were few and at a low level. Day programming was sometimes inadequate. Access to public transportation was sometimes nonexistent. And--home-like atmosphere or not--conformity was required in that residents participated in activities collectively, went to bed and ate at fixed hours, and were forced to fit in a variety of other ways as well. I believe these are practical, and very important, factors to be taken into account, hopefully before arrangements are made for the establishment of the home. If not, by those who must judge its effectiveness.

A nationwide study of homes for developmentally disabled persons, including the retarded, showed that community facilities were better than many had feared to find if they looked (O'Connor). But the researchers emphasized the need for meticulous planning, careful program implementation, and on-going monitoring. They pointed out that the success of community placement is

creating potentially dangerous pressure in favor of deinstitutionalization. Caution must not be thrown to the winds, for the retarded are the ones who will suffer.

They call it normalization

Normalization, in the words of a famous Scandinavian proponent, has become a new "ism" (Bank-Mikkelsen). Without understanding the intentions and implications of the original concept, civic leaders of all sorts, parents of the retarded, politicians, and even specialists on mental retardation jump up willy-nilly and go out to do good in the name of "normalization." The word is in vogue. The idea is dogma. To question normalization is to provoke accusations of heresy.

Yet normalization is mistaken for normality. This is no excuse for the knee-jerk reaction against examining old habits and cherished beliefs in terms of the goal of normalization. But please--consider the original concept. Consider existing misconceptions.

The residence as social system

An institution--and please don't forget that a community residence is a form of an institution--is a social system functioning in an environment (Miller & Gwynne). Scholars and researchers have studied the dynamics of social systems for years, but there is no authoritative literature. Be warned. The factors

involved are complex.

Two British researchers, E.J. Miller and G.V. Gwynne, have written a provocative book about institutions. It is called A Life Apart. What the authors say applies to community residences no less than sprawling asylums and antiquated chronic care hospitals. Miller and Gwynne believe that people living in sheltered circumstances, under the care of others unavoidably are apart from the rest of us. They argue that the boundary between the care-taking facility and the wider society must be acknowledged. They see no reason for society to feel guilty about this inevitable barrier, and they explain some of the ways wishful thinking about removing this barrier can damage the handicapped persons reformers wish to assist.

Significantly, Miller and Gwynne stress that things go awry even when liberal values prevail and great energy is devoted to steering residents in the direction of the greater independence and providing opportunities for growth of abilities. "The philosophy that people are more than their disabilities and the emphasis on development of individual capacities seems unexceptionable. Yet paradoxically, this approach may deprive at least some individuals of their real needs. The pressure to maintain or increase independence may be inappropriate and even distressing..." Dependence,

even when it is appropriate, may become unacceptable. The individual may be forced to distort reality and conform in order to avoid being classified as a deviant or failure.

In fact, the proper function of an institution--whatever its size, whether it is a community facility or not--is to provide a setting in which the resident can find his or her own way of relating to the external world and to himself or herself. The task before us is no more and no less than this.

Conclusion

While I may have certain concerns about the progress of group living in the community, I believe that every retarded child and adult who can should live in an ordinary residence in an ordinary community, with necessary help but without unnecessary restrictions.

We are proceeding. As enthusiasm builds, the great danger is that we will impose our preferences on persons who do not share them. On persons with whom we do not fully empathize, though we may love them dearly (Miller & Gwynne).

We must watch ourselves closely and ask ourselves questions. When community residences are created and retarded people put in them, do we serve the mentally retarded, or do we really serve ourselves? Why do we frown so omnisciently on life apart from the so-called

mainstream? According to what standards do we downgrade human existence in limited circumstances?

We must confront our ambivalences, examine discrepancies between professed attitudes and behavior, and try to distinguish reason from rationalization. This is difficult, but those of us who have responsibility for the lives of others must try (Miller & Gwynne).

Let's not expect a pardon from our responsibility.

WORKSHOPS

SHARING STATE EXPERIENCES - PRACTICES, PROBLEMS AND SOLUTIONS

(Four concurrent workshops on
implementing the IPR process)

WORKSHOP LEADERS:

- I - Keith Cook,
Mental Health Coordinator,
Medical Services Section,
SRS, Kansas
- II - Polly Stanley,
Director, Nursing Home
Division, Medical Care
Foundation, Georgia
- III - Linda Cooper,
Manager, Long Term Care
Unit, Medical Services
Section, DSS, Iowa
- IV - Nancy Searcey,
Long Term Care Supervisor,
DPW, Nebraska

INTRODUCTION

There were four concurrent Workshops on the IPR process, entitled: Sharing State Experiences--Practices, Problems and Solutions in Implementing the IPR Process. The intent was to facilitate the fullest possible sharing among States with varying experiences. In order to accomplish this: Workshops were limited to twenty-five participants each; Workshop assignments were structured to ensure broad State representation within each Workshop; and each Workshop was led by a State person who was directly involved in implementing the IPR process.

Draft Manuals and Workshop discussion guides were developed and distributed to help stimulate and focus the Workshop discussions. Workshop leaders were, however, encouraged to use these materials flexibly and to pursue the topics which were of greatest interest to the assembled participants.

Immediately following the Workshops, each of the leaders presented a brief summary of their Workshop discussions to the re-convened conference. This section includes a copy of the Workshop discussion guides, followed by the summary presentations prepared and delivered by each of the Workshop leaders.

--Discussion Guide--

PRACTICES, PROBLEMS, AND SOLUTIONS
IN IMPLEMENTING THE IPR PROCESS

WORKSHOP FOCUS:

To share specific State experiences with reference to each aspect of the IPR process and procedures, including what is done and how well it works out.

WORKSHOP PRODUCT:

An overview of the dominant practices of States represented in the Workshop, and

A consensus, to the extent possible, on the "best" methods, or combination of methods for dealing with each aspect of the IPR process

TOPIC OUTLINE: (Reference: Chapter II of draft manual)

1) Composition and deployment of IPR teams

Questions: What professional categories are generally included on the core team responsible for doing IPR in ICF's/MR?

What, if any, special qualifications do they (or should they) have?

Are physicians, psychiatrists, or other specialists used on IPR teams? How? With what benefits?

How is the QMRP requirement satisfied? Discuss problems and/or solutions.

Do the same teams do the reviews in SNF's, regular ICF's and ICF/MR facilities? If so, is this a desirable practice--or might greater specialization be preferable?

Do the same teams go back to the same facilities year after year? What are the pros and cons of this practice?

2) Team training

Questions: What special training is provided in relation to implementing the IPR process? Is this general or specifically related to ICF's/MR?

What training--in terms of both form and content--would be most useful in preparing teams to do reviews in ICF's/MR?

What is (or can be) done to achieve a commonality of approach among teams (i.e., to increase inter-rater agreement)?

3) Procedures and approaches for performing the individual assessments

a) Frequency of reviews

Questions: How often is each resident reviewed?

What are the advantages and disadvantages of varying intervals?

b) Workload

Questions: What is a typical workload for a single team (i.e., what number of individual assessments per year)?

What is the optimum workload, per team?

What back-up staff (administrative and support) is needed?

c) Preparing for the site visit

Questions: What is the general practice in relation to advance notification of the facility (letter, phone call of both)? Who is contacted? How far in advance of visits?

What preparation is the facility asked to make?

What is the process for identifying Medicaid-supported residents (e.g., list prepared by facility, list secured from Medicaid agency, previous IPR records)? What are the advantages and/or disadvantages associated with each method?

What is the role of the entry interview? Does it need to be repeated at the start of every review? Who is (or should be) included? What is covered?

d) Individual reviews

Questions: What is the sequence?

What data sources are used

- Face sheet information provided by facility--
If used, what does it consist of? How is it (or might it be) verified?
- Facility records--
Are they reviewed before or after observations? Given their bulk (and frequent dispersal at different locations), how is the record review conducted? How is the record review process divided among team members?
What other complications are there in reviewing records? What solutions have been developed?
- Resident observations/interviews--
How are these handled for residents with varying levels of retardation?

What do reviewers generally look for (or at)?
What do they ask?
How do reviewers deal with the possibility that they may be seeing residents in an atypical situation?

- Staff observations/interviews--
To what extent are facility staff involved in the reviews?
What staff is (or might be) included?
How does (or can) this source contribute to the review process?

4) Feedback and follow-up procedures

Questions: What purposes are, or should be, served by feedback and follow-up?

What is the form, and content, of each aspect of feedback and follow-up, including:

- The exit interview
- The summary report
- The facility response
- Follow-up to verify corrective action

How effective are these approaches?

How might these procedures be improved to effectuate desired changes in facility functioning?

5) Open discussion of any other process areas or issues

WORKSHOP I

Keith Cook

We had a very full discussion of our Workshop and I hope I'll be able to cover most of the points.

We began with a discussion of the reasons for doing the IPR, and we identified a variety of purposes, including: providing technical assistance; encouraging the delivery of quality care; evaluating and upgrading the care received by each resident; establishing the level of care and appropriateness of placement; and continuing to qualify for Federal reimbursement.

In answer to the question about the composition of the teams, we found that most States are using the two-person teams, consisting of a nurse and social worker, with physicians and other professionals serving as ad hoc consultants. Several States have larger basic teams, including a psychologist, speech therapist, or other professional disciplines.

There was considerable discussion about the role of the physician consultant. In several States, medical consultation is arranged on a contractual basis--either through a Medical Society or with other groups of doctors. One State noted that this approach doesn't work--that they are never able to get the doctors out to the facilities; another indicated that

they haven't needed assistance from their physician consultants. In still another State, the physician's role is limited to resolving disagreements between the team and the facility physicians.

About the role of QMRP, it was generally agreed that the involvement of a QMRP is highly desirable because the QMRP can provide special insights into the needs of retarded persons and because it makes the team more believable. Several States have one or more QMRP's on their regular teams. A number of others "borrow" mental retardation experts from State facilities--these borrowed personnel help in doing reviews of facilities other than their own. There was some feeling that this was a drain on State facilities and that IPR teams should hire their own QMRP's.

As far as the deployment of the teams is concerned, most States reported that the same teams review all three types of facilities--SNF's, ICF's, and ICF's/MR. Reasons include staff preference for variety and the economic advantages of assigning teams to geographic areas, rather than to special facility types. Some States do use specialized teams; a few have tried both approaches; and one State offers their teams a choice.

On the question of having the same team repeatedly

visit the same facility, we noted a number of pros and cons. Staff morale, rapport, cooperation, knowledge of the facility and the opportunity to observe change were mentioned as advantages. The main disadvantages were seen as a tendency for the team to become too sympathetic toward the facility or to have a hard time overcoming prior negative impressions. Rotation has the advantage of getting new personnel and new ideas into the facility. Workloads seem to vary tremendously, from approximately 400 to about 3,000 reviews for each two-person team per year.

There was a lot of discussion about the relationship between IPR and survey teams, and a lot of concern about difficulties in achieving communication and cooperation. Particular problems mentioned included one-way communication (that is, IPR teams share reports but surveyors do not) and the fact that the two types of teams frequently convey different messages to the facilities. Some States felt that joint meetings and shared reports had helped a great deal, although at least one State reported that nothing had seemed to help. It was suggested that a third party might be used to bridge the gap. In most States, the IPR and survey teams were separate, but there were a couple of cases where the same teams served both functions. This reportedly works very

well in one State, although most people felt that combining the teams wouldn't work in their States because of the differences in function and outlook, the large number of people who would have to be involved, and the difficulties in arranging follow-up.

WORKSHOP II

Polly Stanley

In Workshop II, we discussed the same processes and questions as those reported by the other workshop leaders. Some of the special points which were raised and discussed in our Workshop included: questions about whether a QMRP must be a member of the review team; the requirement for facility response to identify problems and/or recommendations; and frequency of reviews. A number of the States represented in our Workshop conduct semi-annual reviews and some doubts were expressed about the effectiveness of this approach, since there is relatively little likelihood that major progress can be made, or identified, after so short an interval.

We had a great deal of discussion about whether a team can determine that a mentally retarded person has reached his/her maximum potential and that no further training is necessary. We finally agreed that we should put emphasis on training and habilitation for all mentally retarded residents, regardless of how little potential is evident. That is, we should always assume that there is some potential to be developed.

There was general agreement that it is useful to have a structured review form to use, in addition to professional judgment, in order to help standardize our

assessments. Standardization of the training provided for review team members would be particularly valuable.

Finally, the point was made that our reviews should be distributed to all agencies, including, for example, licensure, mental health, and fraud and abuse.

WORKSHOP III

Linda Cooper

There were sixteen States represented in Workshop III. All of these States use teams consisting of RN's and social workers, and most have physician consultants. Two States use consultants other than physicians and one State uses a four-person team consisting of an RN, social worker, psychologist and teacher. There was a good deal of concern about what constitutes a QMRP; what training is adequate. Instances were cited of persons with extensive, special training who didn't qualify as QMRP's, compared with other cases where doctors, nurses or social workers were considered qualified. The point is that no State really has a procedure for "certifying" QMRP's and the judging process varies widely.

Seven States use the same staffs for SNF's, ICF's and ICF's/MR. Six States use different staffs. Reasons for using the same teams in all types of facilities include the small number of facilities, staff's preference for variety, or simply the way it evolved.

As far as frequency of reviews is concerned, four of the States do semi-annual reviews and the remainder conduct the reviews annually.

We spent considerable time discussing training

and training needs. A lot of different methods are used, including: in-service meetings, on-the-job training, informal one-on-one, participation in training provided by institutions for the mentally retarded, and care of community facilities, for example, college and university courses. Some States pointed out that they hired trained people so the need for training was reduced; the problem, though, is the educational and work backgrounds of new employees varies a lot. In sum, it was felt that a good, special training program would be desirable. It should cover such areas as: the interdisciplinary concept, the special needs of the mentally retarded, components of institutional care and the inter-relationship between IPR and Utilization Review.

The final discussion had to do with the level of care issue. It was pointed out that there are times when shifting clients around may be harmful to the clients; yet, the program is designed to "move people out." Another concern is the lack of alternatives--sometimes, the clients are ready and able to move out and there's no place for them to go.

WORKSHOP IV

Nancy Searcey

Workshop IV included representatives from thirteen States and two Regions. We had a lively and productive interchange about the practices that we use, and I want to thank all of the participants for their contributions.

In terms of the composition of the teams, all of the States use, or plan to use, a nurse and social worker as regular team members. A number also involve other professional disciplines and/or QMRP's. About half of the States use physicians and there was some feeling that this leads to a heavy emphasis on the medical aspects. There was a lot of discussion about the qualifications of a QMRP. Since the definition is so broad, it's hard to know what should be counted as "experience."

The States were about evenly divided between those that use the same teams for SNF's, ICF's and ICF's/MR - it seems to depend on the availability of a QMRP or on the preference of the team members. Also, some go back to the same facilities year after year and others rotate so they won't become too familiar. We got into quite a discussion on what is really meant by the word "independent" - is it really an independent review if it's done by the Health Department, since

the Health Department also runs the program? We decided that the review is technically independent, so long as the reviewer is not actually employed by the facility, although there was still concern about possible conflicts of interest.

There was a lot of interest in training for IPR teams. Several States described their in-service programs - mostly, they focus on how to fill out their forms. Surveyors receive training annually and there's no special training for IPR teams. Also, there's a money problem because surveyors are covered 100% for training and IPR teams only get 75% reimbursement. Region VII has been working for two years to develop a special training program for IPR teams. The proposed subjects include: Medical Evaluation, Social Services, Activities, PT, OT, pharmacy, behavior modification, normalization and nursing.

We also discussed the differences between the survey and IPR functions, what constitutes the various levels of care and what level of retardation requires placement in an ICF/MR.

In terms of the Survey-IPR relationship, one State said that the same team does both and that this has been helpful in terms of communication problems. Another State has tried this approach, but the reactions were mixed. We generally agreed that IPR teams look

at the patient and the plan of care and make the decision on the basis of whether the facility can provide what the person needs. In addition, IPR can say that a person is not getting what he needs. The IPR can also make a judgment about the interdisciplinary team's plan of care, but surveyors just check that it's there.

On the subject of the actual processes used, everyone does the IPR at least annually and some do a second review, for UR purposes, but this isn't so involved.

Budget is the main determining factor in connection with the size of the workload, and there is a lot of variation. In one State, it's felt that three hours is needed for an adequate review of an individual. Others schedule ten to twenty in a day. The amount and kind of feed-back varies a lot too - but there was some agreement on the lack of adequate time for follow-up.

Finally, we discussed the problem of what to do if a resident doesn't want to move or if there's no place to move them to.

ASSESSING ACTIVE TREATMENT IN ICF'S/MR

KENNETH T. KUHLBERG

Coordinator of Educational Programs
Accreditation Council for Services for Mentally Retarded
and Other Developmentally Disabled Persons (AC/MR-DD)
Joint Commission on Accreditation of Hospitals

ASSESSING ACTIVE TREATMENT IN ICF's/MR

Kenneth Kuhlberg

The Standards for residential facilities for mentally retarded persons that were originally published by AC/MR-DD are the basis for the present Regulations for Intermediate Care Facilities for the Mentally Retarded (Title 45 Code of Federal Regulations 249.13). The Federal Regulations are a selected group of the AC/MR-DD Standards. A few standards were combined and some were modified, but these changes were not extensive. There is a substantial difference in the number of standards in each of the two documents. The AC/MR-DD Standards have over 2,000 standards in them while the Federal Regulations contain about 400 standards. Fortunately, however, those 400 standards correspond closely to the set of accreditation standards used to define the meaning of accreditation and subsequently to provide the base for accreditation surveys and survey decisions.

So that is why I've been asked to participate in this meeting: as a representative of the source of the ICF/MR Regulations. Despite the fact that the Standards are written in relatively clear, simple language, there remains considerable confusion about what exactly many of the standards mean and how they were intended to be applied. We appreciate the

opportunity that this significant meeting gives us to share some of the intimate details of the relationship between the Standards and the Regulations, to explain the position of the Accreditation Council in relation to issues concerning the standards, and describe our plans for participating in the training of ICF/MR surveyors.

As one of the programs of the Joint Commission on Accreditation of Hospitals, we are part of a private not-for-profit corporation. We have been pleased to have the Federal Government see us as the source of standards for intermediate care facilities for mentally retarded persons. We do not see our responsibility as having ended with the development of the standards, but as in our accreditation and workshop activities, see our responsibility as largely being comprised of promoting use of the standards and helping anyone who is interested to understand and apply them.

Many have said that the standards are ideal or unrealistic or unreachable. It is true that many ICF's in their present condition cannot meet the standards. Only about one quarter of the public mental retardation facilities surveyed in this country currently become accredited. But as 25% do meet accreditation requirements, they must be achievable. There is currently a big gap between the requirements for

accreditation and the requirements for certification as an ICF/MR. Very few facilities are denied ICF/MR certification, including many that cannot achieve accreditation. A fundamental difference between the two processes that provides part of the explanation is that the accreditation process requires compliance at the time of the survey with the applicable standards defining accreditation, while the certification process allows for compliance either through compliance at the time of the survey or through a plan of correction. The time requirements for implementing plans of correction should rapidly eliminate this difference.

As we all know, there are varied opinions about what many of the ICF/MR standards mean. Many of them are not clear by themselves, but require considerable background information including understanding of principles, concepts, or value judgments from which they are derived. Many words have more than one meaning. And those are the simple problems of understanding the standards. In addition, many emotional issues, including those having to do with the realities of providing services, appear to have a dramatic impact on the way in which the standards are interpreted. We all know that many facilities are old, are overcrowded or understaffed, and that they do not have the money needed for meeting the standards. We know that

we live in a poor country and that the money we do have is needed for other things. And furthermore, no one is really responsible. The problem is so big that only the Federal Government can provide the resources that are needed. But the Federal Government is in debt and has many other priority problems to consider. In addition, the States should not be interfered with and we know that when the Federal Government provides money it then also wants to regulate. And I am not responsible. My job is just to talk about the problem. And lastly, mental retardation was first discovered in 1961. There just has not been enough time or money to do everything needed yet and even if we had the money, where can you find a physical therapist?

But seriously, there are very big problems connected with providing quality services for residents of ICF's/MR. In working on arranging our training program for ICF/MR surveyors, I have sometimes thought that doing the training may be irrelevant and possibly even counter-productive given the pressures to certify. There are going to be many arguments and undoubtedly many unresolved differences of opinion. We are pleased, however, that we have the opportunity to voice the position of the Accreditation Council as to the intent and meaning of the standards regarding active treatment.

Fundamental to successful assessment of compliance

with standards is understanding what the surveyors' job is and is not. It is the surveyors' job to understand the standards, know how to assess compliance with them and to then apply them accurately and reliably. It is someone else's job to decide on the certification or decertification result. The surveyors' decide on whether each individual standard involved is either met or not met. Their job is assessment of compliance and being helpful to the facility in its development of plans of correction. To do these things, of course, requires accurate descriptions of present conditions. That is, it requires the collection of good data. I was talking with a group in a regional meeting a short time ago in which one of the participants expressed surprise that we would suggest marking the survey form "not met" simply because the item was not met. His point was that many facilities have overwhelming problems and marking too many things not met just because they are not met will just add to those problems. The problems being talked about were those of finance and management, not those having to do with residents' needs. If the surveyor does not accurately describe present conditions in relation to the standards, then there is neither a reason for the standards nor the plans of correction needed to correct those things that are officially already met by virtue of not being marked

not met. The surveyor must observe as accurately as possible and decide whether what is seen or not seen concurs with the meaning and intent of the standards, mark the report form accordingly and when needed write an explanatory statement useful in making the certification or decertification decision. Our position is that the surveyor must resist the temptation or the pressure to make policy decisions. The surveyors' job is to understand the standards and apply them rigorously. The surveyors must be allowed to put all of their energies into their data collection activities and not be expected to change the meaning of the standards, to delay use of the standards, grant waivers, or engage in other such activities that are the responsibility of others at some policy making level. Other activities must be attended to by others in order to relate the assessment of the standards to the realities connected with the complexities of providing services to large numbers of people with very demanding needs, and often under conditions guaranteed to frustrate even the best intentions and efforts. But that is the problem. We believe the solution to the problem of sub-standard services starts with good survey data that gives an accurate picture of what needs to be done. We feel that we can help in this by engaging surveyors in training, using their general

knowledge and survey experience, so that they become confident regarding the exceedingly difficult job of assessing compliance in ICF's/MR.

The training program starts with working with the surveyors on the nature and needs of mentally retarded persons. We will provide background material intended to assure all are speaking the same language regarding definitions, etiology, labeling, and the meaning of related conditions and mental retardation as a developmental disability. There will be discussion of the history of institutional treatment of mentally retarded persons with emphasis on moving out of the era of custodial care and into that of active treatment. Characteristics of modern programs will be discussed with individualization rather than mass care, and integration rather than segregation of handicapped people, stressed. There will be information on how developmental changes can be measured and what is needed in setting and assessing the achievement of treatment goals.

We will make sure that all participants are familiar with the developmental model and appreciate its contrast with the illness or hospital model. The participants will be called on to think about and conclude what implications the developmental model has for design and organization of facilities for mentally

retarded persons. The principle of normalization will be discussed with consideration for how it interacts with, and sometimes appears to be in conflict with, the developmental model. Again, emphasis will be on how these principles are relevant in application to residential facilities. Human rights will be discussed, especially as they relate to normalization and personal development. Participants will explore right to treatment issues including the right to special treatment when that is needed.

Most of the time in the training sessions will then be devoted to the basic task of coming to conclusions about what individual standards mean, how they are intended to be applied, and what one does as a surveyor to attempt to reliably and accurately assess compliance with those standards defining active treatment. About one-half of the 400 standards are seen as directly related to measuring the provision of active treatment to residents. We believe that the way to assess compliance with the Regulations is through assessing how they are implemented in the services provided to individual residents.

The surveyor will be looking at these standards within eight topics organized so as to establish a meaningful context and facilitate collection of information and reporting of survey results. This

methodology may or may not subsequently be used by survey agencies, but is being offered because of our belief, developed through survey experience, that such an organization makes the standards much more understandable and less redundant and fragmented through putting related items together. In addition to the advantages to the surveyors of having the standards grouped into topics, we feel that doing so should also facilitate the development and implementation of plans of correction by the facility.

The first topic is Assurance of Rights. It includes issues regarding what the facility's official positions, attitude, and actions are in relation to several standards specific to policies and practices regarding protection and promotion of the residents' rights. The standards in the Regulations that are grouped here are those that require the facility to take an active role in making sure that the residents enjoy the rights that the rest of us do unless legally determined to be incapable of doing so, with no rights abridged without due process and then only to the extent of the person's disability. This group includes the standards requiring protection of financial interests, protection from abuse, having specific consent for certain procedures, and protection from not being paid appropriately for work. Also included are the standards regarding

establishment of guardianship as needed, and the requirements for promoting family contacts.

The second topic is Normalization. Surveyors will be asked to consider what they find in facilities in relation to whether they would consider the conditions normal for themselves, and to determine if there is good and sufficient reason for having conditions otherwise when they are not normalized. Surveyors will be asked to consider what conditions should be, rather than have the principle of normalization obscured by the problems of the particular facility being surveyed. Throughout the training, surveyors will be reminded that the real and sometimes overwhelming problems of operating many facilities must be viewed with sensitivity and understanding, but that they also must be separated from decisions about the specific standards being applied. In applying standards related to normalization, surveyors will be asked to remember that normalized does not mean the local or average range when such conditions are low in status. Though it is true that many people outside institutions live in unimpressive surroundings, the principle of normalization holds that services should be provided within environments that enhance the dignity of the residents and emulate conditions that we value. Individual standards applied under this topic will then be discussed

in order to enhance the surveyor's ability to get information about how integrated the facility is with its surroundings, whether residents are living within normalized conditions and whether the facility is generally organized in such a way as to be normalized or when necessary provide the opportunity to learn normalized patterns of living. This topic includes those standards that state the residents should be able to have visitors without restrictive "visiting hours;" and be able to visit home without undue complications; that require that residents sleep in pleasant bedrooms above ground, with a window, with no more than three roommates, and without too much crowding; that each resident has enough of the clothing needed for normalized living all of which is his or her own and that they use it, and that they have access to their clothing and can also keep other personal belongings in a normalized way. This group includes the requirements for a proper bed, rather than, for example, having people who are too old for cribs sleeping in them just because they might fall out of a regular bed. It includes the requirements that each resident have normalized furniture that they can use. Normalized dining requirements under this topic include that meal times be like in the community, and that all, including mobile-nonambulatory persons, eat in dining rooms and

at tables, with appropriate size tables and chairs and dishes and utensils designed for individual needs, including the need for individualized eating skill development. This section also includes the requirements that all who are or can be made mobile be out of their beds and bedrooms daily and out-of-doors on a year round basis.

The next step will be to understand the Interdisciplinary Process as defined in the regulations and work on how surveyors find out if such a process is actually in operation. This will include using the standards that require interdisciplinary teams composed of persons from all disciplines relevant to the resident's needs who meet together at specific intervals to evaluate the resident's needs, plan an individualized habilitation program to meet the needs identified, and review the resident's response to his program and make revisions as needed. We will work on how to identify who is relevant to each resident's team and who and to what extent various persons are required to participate in the team's activities. This section will include putting together various functions having to do with individual disciplines that must be integrated in order to satisfy the meaning of interdisciplinary process.

Individual Evaluation and Program Planning and Implementation is the next topic that will be considered.

It includes three subtopics: Training, Behavior Management, and Health and Other Personal Development needs. In this section the surveyors will work on determining how to assess the extent to which the facility operates a systematic developmental progression for each resident. We will deal with whether residents are grouped on the basis of similar social and intellectual needs rather than on some other basis that does not promote the growth and development of those grouped together, as required by the standards. This topic includes the requirements that the facility's services be available, as needed, to all its residents regardless of age, degree of retardation or other handicaps. This section includes the obligation to maintain records adequate for operating active habilitation programming that includes documentation regarding whether placement was initially and continues to be appropriate, whether comprehensive evaluations have been conducted, whether reviews are made at regular intervals using adequate information, and whether needed services are planned and provided for before a person is transferred from the facility.

The Training subtopic will include emphasis on the fact that most residents of ICF's/MR experience great difficulty in learning even the most basic developmental skills. Well conceived and implemented

training programs are therefore needed or little learning of significance will occur. The surveyors will be asked to accept the fact that training must be carried on systematically and rigorously if the requirements for active treatment are to be met, and that systematic training includes, at least, specifying the behavioral objectives of the training, the methods to be used, the training schedule, the person or persons responsible for conducting the training and the data that are to be collected in order to assess progress toward the objectives. Attention will be given to assessing whether the living unit staff in cooperation with others are appropriately involved in their primary responsibility of promoting development of residents including through the use of systematic training.

Within the Behavior Management subtopic, it will be pointed out that much of behavior management is or should be an extension of the general training requirements. The regulations imply positive approaches to managing the unwanted behaviors of residents rather than simply punishing or otherwise attempting to control those behaviors. The surveyors will be asked to expect, when problem behaviors are interfering with residents' progress, that there be priority training objectives being pursued to replace or modify those

behaviors. In addition to understanding the requirements for positive approaches to behavior management, careful attention will be given to considering how to determine whether other behavior control measures, such as drugs and restraints, are being used in compliance with the regulations. The regulations assigned to this topic require that drugs and restraints be used only as part of the person's treatment plan, designed by the team in a way that would be expected to reduce or eliminate use of such controls. This group, of course, also includes those standards prohibiting corporal punishment and use of seclusion rooms, and limiting use of time-out devices and aversive stimuli to carefully planned programs with proper review, consents, and other controls as required by the Regulations.

The subtopic Health and Other Personal Development Needs will be used to round out consideration of whether each resident is receiving appropriate attention not only in developmental programming, but also in the various other personal need areas that must be attended to in providing comprehensive care. For the most part it will be suggested that assessment of specialized services be done separately from the assessment of the active treatment regulations. It will also be suggested, however, that deficiencies found in the special services

areas be reported under this topic in order to integrate the information and emphasize that no service should exist in isolation from the rest of the habilitation programming activities for the residents.

The last topic to be worked on will be Staffing and Staff Training. The importance of sufficient staff will be considered with the knowledge that it is usually impossible to make reliable statements about exactly how much staff is needed given the differences in populations of facilities, the physical aspects, and such things as the level of training and the general efficiency of the facility's operations. It will be suggested that surveyors first identify whatever deficiencies exist in the provision of treatment as needed, and then consider the possible reasons for such deficiencies and conclude whether the reason, or part of it, is lack of staff. Making sure that all are familiar with the requirements concerning minimum staffing ratios in the Regulations will, of course, be included. But emphasis will be on understanding that those ratios are minimal, and that to carry on active treatment as required by the Regulations, more staff will often be necessary. This topic will conclude with consideration of what the regulations require of the facility in the training of its staff.

Now that we have pulled out what we have called

the active treatment regulations from the total set of regulations we feel that it is only right that we put things back together again, so that this training will be useful and applicable to surveys rather than another complication or burden. In order to do this we will then briefly discuss suggestions for integrating all of the regulations with a listing of all of the standard numbers using the simplified numbering system that thankfully has been provided by the authors of the Federal survey report form. It is hoped that survey agencies will find these arrangements useful to them in organizing their surveys.

After wrestling with big social concepts, philosophy, terminology, history, and methodologies, and dealing with a multitude of diverse standards, it is expected that there will be related concerns about what to do with all this in relation to the realities of conducting surveys. The last half day will be devoted to an open discussion about problems of surveying. During this time, persons with varying amounts of survey experience will be asked to share that experience with others who are involved in or affected by surveys for the purpose of integrating the training with the real problems that exist in conducting effective surveys and in order to arrive at practical suggestions for solutions.

And now it's your turn to identify problems, raise questions, or make comments on what I've just said. I feel very fortunate to be able to present this material to this relevant group and would now love to hear whatever thoughts you might have about what has been presented, or points of interest to you that I have avoided or otherwise not mentioned.

HOW TO DESIGN AND EVALUATE
A DEVELOPMENTAL PLAN OF CARE

WARREN BOCK

Mental Retardation Consultant,
MR and DD Division
Minnesota Department of Public Welfare

and

KATHRYN ROBERTS

Coordinator,
Deinstitutionalization Model Project
Minnesota Department of Public Welfare

Warren Bock

Before I get into the presentation that brought me here, I'd like to tell you a little about a project that might be of special interest to you. There has recently been awarded to a consulting firm, called Government Studies and Systems in Philadelphia, a contract to do a critical analysis of all the existing rules and regulations that affect programs for the mentally retarded, especially those who are in ICF's/MR. They reviewed literally hundreds of rules, regulations, standards and criteria that affect both compliance and quality assurance mechanisms (Q.A.M.'s). And I'll take just a few minutes to share their preliminary findings with you.

This next sentence is a direct quote from the draft report that I just received: "Even though the vast majority of existing standards expressed worthwhile sentiments and recommend useful and effective practices, nevertheless there are recurring defects that limit the usefulness of these standards and the Q.A.M.'s in improving services for persons with developmental disabilities. These defects in technical design, in validity, in reliability, in suitability for the target population render the standards and Q.A.M.'s ambiguous, obscure, or inappropriate."

They've categorized or classed the defects in five general categories: The first, is a lack of measures or scales. They indicate that the standards "fail to meet the widely accepted definition of standards because they lack a measure, scale, index, or any other list of criteria. Most statements were found to be statements of philosophy, or policy, or a definition of service names. In many cases, our reviewers shared the goals and ideals contained in the statements, but they realized that these statements simply lacked the minimal technical characteristics necessary for a statement to be useful as a standard of quality in a quality assurance mechanism."

The second category of defects is the lack of relevance for persons with developmental disabilities. Standards in this category include those concerned with the proper management and administration of programs and facilities, and to an even greater extent, those related to generic services which are provided without special adaption for developmentally disabled individuals.

The third category of defects, and the one I find the most serious, is the lack of reliability. The most common weakness, the defect that undermines hundreds of otherwise well constructed standards, is the lack of precise instruments, clear criteria, and

other reliable measurements. They cite as an example the prolific use of words such as adequate, sufficient, appropriate, and terms such as review, explain, communicate, assist, involve, demonstrate, make available, facilitate, integrate, encourage, ensure, or give consideration to.

The fourth category of defects in the standards was the lack of sensitivity to the rights and needs of persons with developmental disabilities. They suggest that many of the current criteria and standards are insensitive to, or out-of-touch with contemporary concepts of human service. The standards ignore the need for age-specific and culture-specific approaches in expectation. The standards also tend to be over protective, particularly in their emphasis on residential programs with little attention paid to the rapidly emerging field of community-based services. In this same connection, there is still considerable evidence of the medical model for human services, rather than the educational or developmental models currently preferred. A consequence of this orientation is a tendency to over-professionalize, to confuse the need for services and functions with the need for specialized personnel whose job titles resemble the names of those functions and services.

Further, many existing criteria and standards are

not suitable for implementation in both community and institutional settings. This is a consequence of the fact that a large number of standards were created initially to eliminate the deplorable conditions in large residential centers and thus do not reflect the recent emphasis on normalization and deinstitutionalization.

Finally, the last category is the lack of a single-coherent service review process. Service providers are subject to several overlapping review processes, and none of those overlapping processes has all the components essential to a quality assurance mechanism. Kathryn Roberts will be talking about an attempt that we are going to propose to address that particular issue as soon as I finish.

That summarizes what they have done in this particular project, so far. Now, I'll get to my subject.

The Minnesota Developmental Programming System (MDPS), as implied by the name, represents a comprehensive package of materials, procedures and training the purpose of which is to enable individualized developmental programs, or plans of care, to be designed for mentally retarded and similar persons. The system is comprised of the Behavioral Scales, a Technical Manual, a User's Manual, a Training Manual

and program of project operated in-service staff training, a scoring system and a report back system which provides the users with profile information and optional retrieval of materials and methods for individual program design.

The MDPS was designed to provide assistance to three levels of persons in the field of developmental disabilities. They are:

(1) The management level. The MDPS provides summary client data for decisions affecting both resource allocation and program administration.

(2) The program personnel. The system has been designed to provide a staff development model for individualized Program Planning, an instrument for conducting an objective behavioral assessment, the methods and materials to design and implement individualized program planning, procedures and format for on-going performance-based evaluations, and a standardized language for multiple agency personnel planning for client needs.

The System can also benefit the developmentally disabled individual by providing for broad-based planning by an interdisciplinary team, allowing for client input into the program planning process, and, by forcing on-going staff attention to each client's developmental growth, it assures that programs are

individually tailored to each client's needs.

The MDPS was developed because of the dramatic changes which are generic to the delivery of human services across this country and abroad. These changes include the need for more practical perceptions of handicapping conditions, a rapidly growing and radically changing service system, and a decided move toward result-oriented management of human services.

The developmental disabilities, especially mental retardation, are currently being perceived as dependency-creating conditions which have global impact on the lives of the affected individuals. Contemporary definitions of disability tend to focus upon specific behavioral or performance deficits which are measurable and which may be addressed by service programs.

Service delivery has grown markedly in recent years -- in size, in technical method and in expectation. The purpose of services is increasingly that of reducing the individual's dependency through the improvement and maintenance of adaptive behavior. This makes it necessary for programs to target upon specified behaviors, and to do so within a useful framework of behavioral description and measurement.

Funding and monitoring agencies are no longer content with evidence that service effort is being expended; they increasingly require that results be

attained. This kind of result-oriented management must be instrumented by competent methods of measuring the output in terms of client benefit. Reduction and minimization of dependency, or the improvement and maintenance of adaptive behavior, is the most direct kind of client benefit in the field under discussion.

A final trend, growing out of the foregoing, is to implement human services on the basis of individual, tailored service programs.

The range of the individual differences of mentally retarded and developmentally impaired persons is so great that some focus is necessary. The focus of MDPS in its present form is upon broad mid-range of age ability within this population. It is anticipated that specialized extensions of the MDPS will be necessary to most effectively deal with the very young and the totally dependent person and there is some evidence that additional instrumentation will be needed to deal with persons who have approximately normal life competence or who are very old.

We currently are testing alternative Scales for the very low functioning individual and expect final printing of this form by January, 1978. Additionally, experimentation with the MDPS in Skilled Nursing Facilities (SNF) in Minnesota have given us sufficient positive results that a broad-based application of this

System with geriatric populations is planned for February, 1978.

The "heart" of the System is the Behavioral Scales. These are provided in booklet form. Instructions for scoring are given and a record form is provided which is designed for machine scoring. The record form has a required section for client identifying information and for recording certain basic information about the client. It also has a section designed to allow the user to build additional client data structures so that the scores can be systematically related to information that is pertinent to the particular service program and so that useful client information can be assembled for the service program at the time of MDPS scoring. In recording behavior with the MDPS scales the user is instructed to observe the behavior directly or consult with someone who has observed appropriate occasions for the individual to perform this behavior.

MDPS Behavioral Scales assessment data and all personal, diagnostic and administrative data are collected on one response form. These data are scored, analyzed and displayed via computer with turn-around time for users ranging from five to seven days. Data analysis programs to treat these data have been written, tested, and are operational. Additional

programs are available for unique needs of agencies upon request. For example, the Metropolitan Placement Unit of the New York Department of Mental Hygiene came up with some rather esoteric information needs on the Willowbrook class members for whom that Unit is responsible. In Massachusetts, where that State is planning on adapting the MDPS, those folks decided to include some measures on the degree to which their programs meet normalization criteria.

The System was purposely built to accomodate different and changing information needs of programs and administrators.

The MDPS Scales consist of twenty behavior statements in each of eighteen domains. The items are descriptive statements of behaviors such as "Listens to a story for three minutes" (representing the domain of receptive language) and "Arises and leaves from residence so as to reach work or activity on time" (representing the vocational domain). The items are scored in terms of whether the individual produces the given behavior always, more than half the time, less than half the time, or none of the appropriate occasions for such behavior. Detailed instructions for securing and recording information are provided in the Scale booklet.

The Scales are divided into eighteen domains.

These domains are categorized functionally, with each domain representing a broad class of activity as indicated by the domain scale titles. Those domains include gross motor, fine motor, eating, dressing, grooming, toileting, receptive language, expressive language, social interaction, reading, writing, numbers, time, money, domestic behavior, community orientation, recreation and leisure-time activities and vocational skills.

The data that are produced from administering the scales then form the basis for generating individualized program plans with measurable goals and objectives. The system is implemented with an intensive training program that teaches program staff how to develop those goals and objectives. Upon completion of that training component, staff must simulate an interdisciplinary team meeting using either actual data on a known client or a hypothetical client on whom a case history is provided. We believe this component (the training) represents the most critical aspect of successful implementation. Five years ago, before we decided to develop the MDPS, we reviewed other Systems looking for something that would meet our needs in community and hospital-based ICF/MR facilities. The most glaring deficiency we encountered was the lack of any implementation scheme that glued all the pieces

together from assessment to goal planning, periodic evaluation and program redesign to overall program evaluation at the management level. Several of the "pieces" existed, but no system had it all together.

To date, over 15,000 mentally retarded persons have been assessed and are in our data bank with over 3,000 staff persons trained in the use of the system. We're not sure exactly how many programs are using the System nationally, but we've filled approximately 1,000 requests for materials from about thirty States.

The last characteristic of the System I want to talk about is the applicability of this System to the Quality Assurance process. While the original impetus behind the development of the MDPS remains the training of staff and the provision of instrumentation and procedures for developing individualized program plans, or plans of care; the notion of using those data produced by the System as the empirical base for assuring appropriate quality programs to individuals appears more and more reasonable to me. Given the two basic methods of evaluation (e.g., criterion referenced and standardized) it seems to me this system begins to address both. The Behavioral Scales represent the standardized aspect that measures client change on an annual basis across all programs while the goals and objectives produced in the teams

represent the criterion referenced component which can be validated for congruence with perceived client needs by both the treatment teams and/or the QA teams.

Obviously we need more research in this area and are hopeful we can secure some additional research and development support for this application. Further, we want to actively investigate the application of the model or a modification of it, to nursing homes which I've been told by experts in that field could use some help in the area of programs and broad-based information management.

In conclusion, I want to thank Pacific Consultants for the opportunity to share our experiences with the MDPS. Probably the most exciting part of it was the merging of the technology of the computer industry with human service programs. The new hardware we're using is allowing us to do things in the area of information processing and research evaluation that previously we only dreamt about doing.

The other really rewarding part of the experience were the training sessions. Staff have been very reinforcing in their evaluations of both the materials and the training and those programs which started with us nearly four years ago are still using the System.

As I indicated earlier, we've learned alot and

have come a long way in this field in the past four years but expect to go much further.

Kathryn Roberts

Minnesota has been committed to the process of deinstitutionalization for several years. This commitment has been the result of support by the Governor of Minnesota and the State Legislature.

This State, specifically the Department of Public Welfare (DPW), has been the site of several projects aimed at understanding and managing the deinstitutionalization process. Review of these efforts are summarized below:

(1) In 1974, a Technical Assistance Project grant was awarded to the Minnesota Department of Public Welfare that provided four persons the opportunity to assist those who were developing new community residential facilities (CRF's) and to aid existing facility operators in the process of compliance with State programmatic licensure and Federal Title XIX compliance. At the conclusion of that project, eighty-one new community residential facilities had opened, and all those facilities who had chosen to be funded by Title XIX had been certified. This project provided the Department of Public Welfare with valuable information about individual programs and facilities by providing data related to size of program, type of program and the level of compliance with licensure and certification.

(2) Simultaneous with this project, the Minnesota Developmental Programming System (MDPS) Project provided information to the facilities about their clients in the form of specific behavioral data. A behavioral assessment is completed on a yearly basis and reported to a central source for scoring and display. The Project provides not only individual data, but summary data on unit, facility or State level. It is this project that provided a second data base to the Department of Public Welfare.

(3) Additionally, a study was conducted in the Mental Retardation Program Office, that sought to specifically identify clients within the State institutions who were ready for community placement. This task was completed and reported in a study. However, we had no existing mechanism to assure that these placements were made, or that those placements that did occur were appropriate in meeting the needs of the clients, as we had no method to track these identified clients' movements.

(4) A selected group of Mental Retardation coordinators housed in local Mental Health/Mental Retardation Area Boards organized a task force whose mandate was to develop a mechanism for collecting comprehensive data about clients receiving services. This data would supplement behavioral data that is

already available through the Minnesota Developmental Programming System project. This data collection effort presumed a high level of coordination among service providers regardless of the State agency supervising their activities.

Therefore, the Minnesota Mental Retardation Program Division had available information about the behavioral level of clients, additional client service data, specific facility and program information, a background in interagency communication and experience in Statewide data collection. All of these components were developed and maintained based on the assumption that deinstitutionalization is an on-going dynamic process. However, one piece was missing. We had no single mechanism that allowed us to cohesively use available information to effectively manage deinstitutionalization in our State. It was this realization that led to submission of a grant to the Region V Developmental Disabilities Council for funding. It was a grant stating the objectives necessary to manage the process of deinstitutionalization in Minnesota.

The Minnesota Management Model for Deinstitutionalization consists of phases that are to be conducted simultaneously. Those phases are described below.

Phase I: Client Data Collection

In conjunction with the Minnesota Developmental

Programming System project, a data collection format will be created that records client characteristics. These data items will include descriptions of the client (age, sex, disabilities) and behavioral data that reports the functioning level of those persons. This collected data will be submitted to a central site for analysis. The profiles will be requested on an annual basis. Thus, if thirteen months pass without an annual report, a signal from the central analysis site will indicate the "loss" of a client and the appropriate agency can be notified. It is hoped that this process will facilitate tracking clients' movement through the continuum of care.

Phase II: Facility Data Collection

The Project staff will develop a new process for determining facility compliance with Federal Intermediate Care Facilities for Mentally Retarded certification. The process will be completed by use of a self-survey process on the facility site. Several unique characteristics will be evidenced. The process will combine all State and Federal requirements, be initially completed by the program administrators, and be reported to the single State agency on a computer-scored form.

If the facility reports noncompliance on any item, they will indicate what is needed to comply (i.e., more staff), and what the cost will be to the facility to

come into compliance.

The results of this self-assessment will be reviewed by a multidisciplinary team who will serve two primary functions; the team will review the self-reported survey to check for accuracy of reporting, and provide technical assistance to the facility. This technical assistance role will place the survey team in the position of helping facilities rather than being seen as the "bad guy"--a unique position for any surveyor.

What will happen to this data? Two current data files, one containing client information and one containing facility data, will be available. The files will be compatible so that the following results are evidenced.

(1) Client needs can be matched with programs and services that are most appropriate. Information regarding specific programs will be readily accessible to both State and local users to aid placement decisions.

(2) Reliable data on staffing levels (via the self-reporting compliance form) will be available. This information, over time, will provide better insight into the best "fit" of staffing level necessary for discrete levels of care.

(3) Specific characteristics of programs will allow the State to study their continuum of care. With this picture and individual client data, decisions

for expanding services can be made based on identified needs rather than best guesses.

(4) The State and local agencies will be able to monitor client movement throughout the State. Actual use of a continuum of care and movement to less restrictive environments can be documented.

(5) An accessible, easily understandable data base will be available to local mental health centers, county welfare departments and State decision makers. This will assure that decisions made, regardless of the level, are based on consistent, reliable information.

The Project staff foresees other benefits from the grant. It is expected that much of the information collected will be useful to State Independent Professional Review teams. The data will be available to other agencies for use as they see fit.

For the duration of the Project, a policy Advisory Board consisting of representatives from the Department of Health, Education and Welfare Office of Long Term Care, the regional Developmental Disabilities Council and all effected agencies in Minnesota will be maintained. These representatives will facilitate the Project staff in the development of a Management Model for Deinstitutionalization.

WORKSHOPS

ASSESSING THE QUALITY OF CARE

(Four Concurrent Workshops)

WORKSHOP LEADERS:

- I - Marian Lewis
- II - Byron Peterson
- III - William Jones
- IV - M. Jeanette Martin

INTRODUCTION

There were four concurrent Workshops on Assessing the Quality of Care. The twenty-five-person groups established for the Process Workshops remained intact; but there were different Workshop leaders. In this instance, Workshop leaders included State personnel in varied positions (e.g., a facility administrator and an occupational therapist, as well as IPR team members and coordinators).

Discussion guides, focussing on the issues raised in the manual chapter on Quality of Care*, were developed and distributed. As will be seen from the Workshop reports, these guides were flexibly utilized; and each group developed its own special focus.

Following the Workshops, Workshop leaders presented reports on their Workshop discussions to the full Conference. This section includes a copy of the Workshop discussion guide, followed by transcriptions of the Workshop leader reports.

*Note: The Manual has since been revised to incorporate some of the suggestions made by the Workshops, and it is being published under separate cover.

--Discussion Guide--

ASSESSING QUALITY OF CARE

WORKSHOP FOCUS:

To exchange both conceptual and practical approaches to making an assessment of the quality of care received by each individual resident in Intermediate Care Facilities for Mentally Retarded. Emphasis is to be placed on the content of the assessment, since the form, or method, will already have been addressed during the process Workshops.

WORKSHOP PRODUCT:

Consensus, to the degree possible, on:

- Criteria and indicators to be used in assessing quality
- Areas which should be included in the assessment instrument

TOPIC OUTLINE: (Reference: Chapter III of the draft manual)

1) Definition of Quality of Care, from an IPR perspective

Questions: Is it agreed that the standards collectively define the quality of care which must be provided?

Is it further agreed that the IPR process is concerned with applying these standards to individual residents, rather than ascertaining compliance with the regulations in general?

If so, is it true that there is freedom to identify and select those aspects of quality which have the greatest relevance for individuals rather than attempting to cover all quality issues?

2) Dealing with subjectivity in assessing quality of care

Questions: Is there concern about inter-rater reliability in the assessment process, resulting from the heavy reliance on professional judgment?

What approaches have been developed to address this problem?

Would the formulation of more specific criteria be helpful?

Would States prefer to have a standardized instrument for making the individual assessment or do they like the present approach (wherein each State develops its own instrument)?

3) Examination of the elements which comprise quality of care

- a) Adequacy of the comprehensive evaluation
- b) Assessing the active treatment program
- c) Assessing the achievement of normalized living conditions

It is suggested that this section comprise the focus of the discussion. In particular, it would be useful to go over each of the criteria and indicators in the manual, in order to determine:

To what extent participants agree with the criteria and indicators

How they would modify them

What additional criteria and indicators they could suggest (and/or do they use)

(E.g., no criteria and indicators are given with reference to the social services area, to physical therapy, or to several other aspects of the active treatment plan--additions in these areas would

greatly enhance the revised manual which will be developed on the basis of Conference input)

4) The role of instrumentation in assessing the quality of care

Questions: To what extent does the individual assessment form determine the content of the quality assessment?

What do the instruments in current use include which bears directly on assessing quality of care for the mentally retarded?

What areas should be covered in the instrument in order to guide the assessment of quality?

What is the optimum length and form for an individual assessment form?

5) Data sources used for assessing the quality of resident care

Questions: What do (should) you look for when reviewing ICF/MR facility records?

What is (or can be) accomplished through direct observation of, or interviews with, residents?

What is (or can be) accomplished by observing, or interviewing, staff members?

WORKSHOP I

Marian Lewis

I represent team one. We spent some time differentiating between eligibility for medical assistance and certification for ICF/MR. After we resolved that, we went on to generally agree that the standards were a good beginning. We would appreciate some guidelines, but few of us wish to be any more restricted than we already are in our professional functioning--functioning as professionals and making professional judgments. We like the freedom to function in this area.

We addressed inter-rater reliability. Many States are relying on continuing in-service education, with supervisors working with their staff on standardizing their interpretations. One State does have a formal testing procedure where two teams go through the Review Process, reviewing the same twenty patients on the same day--trying to come up with some sort of agreement, establishing some sort of reliability. They are close, but their recommendations continue to reflect their personal biases, regardless of how much in-service training on philosophy and techniques is provided--but it's getting better.

Our group did not want a standardized form for making the assessments of quality of care. We felt

that there were enough regional differences that we would be more comfortable with using our own form and it would be easier for in-service teaching. Rather than the individual States having to interpret what the Feds meant by what was written on their forms, at least we might understand what we are writing down and would perhaps make a more accurate judgment.

We didn't spend a lot of time and examination on elements of quality of care. We knew it was a hot issue and I think we kind of avoided it.

One more time, we want to retain our professional freedom--we don't mind guidelines, but we don't want any more regulations or restrictions.

What do we look for in doing the ICF/MR records? There were some concerns expressed that it depended on who we were--whether we were nurses or social workers--and what we looked for when we reviewed the medical records. It's difficult, but not impossible, to avoid the medical role when we are in an ICF/MR if we are nurses. We certainly rely on the social workers for consultation to the nurse when she reviews the records. We generally agreed we couldn't do a review without first looking at the medical records or the programming records and then interviewing the staff and interviewing the residents.

There is no way we could leave the patient record out of this.

There seemed to be some discussion at the very end that there may be a great budgeting difference between States and perhaps this has some bearing on differences in time; differences of patient caseloads.

We generally agreed that it was the responsibility of the supervisors or coordinators to provide staff training. If there are immense problems, perhaps they have some homework to do in identifying problem areas and seeing what can be done. We raised more issues than we could resolve.

WORKSHOP II

Byron Peterson

Our group was group number two. We had an interesting and I think a productive discussion. We collectively agreed that we need a standardized record form and we feel that this would be an especially important benefit for new staff and for multiple teams operating in a given area. It would bring about more effective standardization of the functioning of those teams. We also felt that the review form should have certain elements that are rather specific as opposed to a more open-ended review form, even though we like the idea of the flexibility and freedom in more open-ended forms.

We talked about the time that we had for conducting reviews. A 15-20 minute time frame seemed to be pretty common. We felt that the use of a cumulative data gathering process was a good one rather than to start from point zero each time and do a fresh review. This would provide consistency and clearer follow-up on previous recommendations, and it would very definitely speed up the process.

In talking about forms, we looked at the Minnesota and Utah forms. We sought some specifics on areas that might be covered in a standardized review form. We didn't develop them. We weren't able to put anything

down, and we weren't really able to accept the Utah and Minnesota forms carte blanche. We felt that there needed to be some differentiation in the form. We felt that these particular forms were more appropriate for higher functioning residents. There would seem to be a need for a form for the more severely retarded and multiply handicapped resident.

We talked about the sources of data--the kinds of things we look for in the chart and the kinds of things we look for in observation of, and dialogue with, the patient. We talked about appraisal of the living unit, environment, and the presence of meaningful programming, normalization routines, and atmosphere. We talked about getting data from the ward care staff, and felt that often you can get some very good input on problems, needed direction and the like from staff. Sometimes you can't--sometimes they aren't really free to relate what the problems are. To tune in on what the problems are, we felt that the use of occasional unannounced or off-hour visits were helpful.

We looked at the criteria to judge quality of care. They start off, as you know, with a focus on getting a sense of the interdisciplinary functioning of the care team. Some of the group members had sat in on the interdisciplinary team that was, in fact, developing the care plans. From that experience, they

were able to sense the team functioning as a balanced unit, and they were certainly able to see if ward care staff were there, if the parents were there, and if the resident was there. That seemed, at least to me, to be a novel and effective way to cut right through and get a quick appraisal.

We pretty much liked all the criteria and the examples given. We had some confusion about the distinction between goals and objectives. It wasn't really clear to us. This is not to imply that it's not clear in the manual, but it needs to be made clearer to us as reviewers. We felt that there needed to be more examples on how to promote individual interaction and appropriate socialization on the living units. We found the manual a little wanting for good examples as to how this could be measured. We were a little ill-at-ease with reference to a comment on the need for patients to become tolerant of the behavior of others. This brought to mind the aggressive patient who is a danger not only to himself, but to others. We weren't sure just how that could be appropriately dealt with. We knew that restraints and quiet rooms were supposedly kind of a no-no, and we were aware that the use of psychotropic medications and the use of mental health behavior management techniques were in vogue--yet we are hearing that they are quickly

going out of vogue in favor of getting more staff and programming to accomplish this end. We were trying to sense where we were at this point in time in the whole process.

We talked about normalization some more, and we felt that there was pretty good contact with the community. We felt that there was a pretty normalized kind of living routine within the institution. We felt that there was a pretty healthy contact with the community, but this contact doesn't seem to be truly integrated. It was kind of a group going here, and group going there. If you used the community swimming pool, it might be that you were the only ones there. It wasn't a truly integrative experience in most cases, and this was something that perhaps we needed to encourage more of.

It was felt that there might be a weakness in that we are there doing the reviews during the day. We had an uneasiness as to what the evening routine was like, and very definitely, what the weekend routine was like. We didn't know whether the residents had typical normalized weekend experiences similar to our own.

I guess I might quit at that.

WORKSHOP III

William Jones

I represent group three. Before I get into the report, I'd like to raise a question concerning content. I'll just raise the question and leave it for future examination because we all are raising more questions than we are providing explicit answers. If we look at the content (in the assessing of the quality of care) we see that it emphasizes medical, educational, developmental and normalization models. However, if we look at the composition of the teams providing the evaluations, we see that they are not educational or developmental in their preparation and training. Also, there may be questions about the team member's understanding of the principle of normalization and its application--whether in an institution or any other service setting. I raise these questions as a general concern.

I take this opportunity to thank the members of our group. We had a very interesting, lively, and I think, thorough discussion--again, raising issues.

As we examined the content question, we began to see it as a "what" question--as an end-product--and we perceived that the standards, the criteria are adequate--that they are sound. So it's not really an issue of promulgating more--or trying to translate

more--criteria.

We perceived that the real problem was not one of content per se, but rather that the issue was one of dealing with the process of interpretation by the IPR team. It was more of a "how" or "means" question--a question of how to apply the criteria to the content areas and to standardize this process. Without standardized "guidance" tools, there was concern about the possibility of marked variance between States--in terms of what is an acceptable standard of care. As a result, representatives of a number of States felt that there needs to be an attempt at standardizing the interpretive guidelines and process. The group felt that there wasn't time--in the two hours we had--to really examine the specific criteria in the manual. Instead, we recommend that a special task force be appointed to develop a set of draft interpretive guidelines which could become a model for the IPR process. The point was made that such guidelines should be suggestive; that is, they should be made available with the provision that States could elect to use them or not.

A second major area that we discussed was the competency, or functioning, of the IPR team. On the one hand, we are asking the facility staff and interdisciplinary teams to provide a certain level of

competency--to be very explicit in their documentation. We are training survey teams, to have certain competencies. Then, when we get to the IPR teams, there are some major breakdowns. Our recommendation, therefore, would be to apply training in research and evaluative skills to the IPR teams, and to increase their professionalism as evaluators--whether they are social workers, physicians, or whomever. The development of evaluation skills could make this a much more rational, objective process. If the team members were provided with specific competencies for performing evaluations, they could be much more effective in making such evaluations or assessments. In turn, the facility being evaluated would have to be more explicit about: the problems they are solving, the objectives they're trying to achieve, the program/process definitions that they are going to use, the use of resources, etc. The task, therefore, is to define the interpretive guidelines and to train the IPR teams so that they will have the competencies to provide explicit evaluative skills.

I'm open to the group to add anything more.

WORKSHOP IV

M. Jeanette Martin

There was consensus on the following points:

(1) Standards do not define quality of care.

They do however, provide: (a) minimum components of service and (b) elements of care. But they do not cover the attitude of the staff, which is very important to the effectiveness of care.

(2) The IPR process was not seen as currently effective in applying the standards to individual resident needs because it is very difficult to enforce these standards when a deficiency occurs. Also, with the current workload, it is difficult to schedule repeat visits to a facility. Discussion further revealed a diversity in general review techniques, length of time for each review, and type of team members.

(3) The group stressed that the regulations are the legal tool, but certification does not apply to resident's programmatic needs. One method suggested would be to take the case to the single State agency and request decertification of the facility.

(4) The group was divided on the freedom to identify and prioritize aspects of quality which have the greatest relevance for individuals, rather than concern for all quality issues. The group felt that

further discussion needs to be made on that point.

(5) Criteria which are general, broad and which define areas of programming can be defined at the Federal level providing States would not accept it as the minimum level of effort. The States should be allowed the option to develop special criteria peculiar to their operation, which are above and beyond the Federal criteria.

(6) The group felt that it would be helpful to have a listing of services offered at the facility and their consultant services prior to review. The elements of quality care review would include:

(a) the patient record, (b) observation of patients, and (c) discussion with direct care staff and interdisciplinary program team workers.

(7) Concern was expressed that the consultant physician's time is taken up with too much paper work and that the physician should be able to review the patient personally and not via the patient's chart. It was felt that some other system could be devised so that the physician could spend more time with the patient. Consensus was reached on the point that clarification is needed in the Draft Manual on the Medical Services Section, pages 29-31.

(8) It was the consensus of the group that the manual has a good framework. However, the jargon

needs to be removed and simple directions and steps need to be added.

The group recommended the following:

(1) If participant States have developed a common assessment tool, please send 100 copies of the tool, directions for use, a sample summary report, and a description of the composition of your IPR teams to Ginger Hale at the Institute of Medicaid Management. She will collate reference packages for disbursement to interested State agencies.

(2) When the minimum Federal criteria and national assessment form are developed, the group would like to have representatives from each State assist in this endeavor.

Question from the floor:

Ginger Hale (Federal resource person)

I have a question for the groups. It seemed that three of the groups liked the idea of a standardized form--one group didn't. I wanted to pose the question I asked in the workshop I sat in on. While a lot of us don't want to give you a standardized form, we do want to help you so you can provide the minimum information that the Federal government feels it needs. The design of a form, etc. is up to the States--as long as you collect the information we asked you for. You can add, subtract, multiply, whatever you want to do. How would you feel about that?

Panel responses

Byron Peterson

I think that when we looked at the Minnesota and Utah forms, we couldn't really fully accept them. We really value a lot of freedom and opportunity. I think that--in my own mind--I saw the solution as being that what we needed was just a skeletal kind of a form with a lot of open space in between.

William Jones

I think it's great to have State autonomy, but when that autonomy isn't structured in some way, and when you don't have a quality product, then you invite

structure--you invite outsiders to come in and tell you how to do your job when you're not doing it.

Maybe we can stand on professionalism and say, for example, I'm a psychologist and therefore I have immunity to anyone else examining me. But, that isn't the issue. I think we can submit ourselves to a process of evaluation--other people do. If you go into business you can be held accountable, and, I think, we too, can be held accountable. I think that we can create the evaluative structure for that accountability--or others will create that structure for us. As reported, we recognize the need for the form and support its development and implementation.

Marian Lewis

When we devised the form for Minnesota, we also developed a thirty-page instruction booklet that goes to each individual team member that interprets the standards. We were very careful to research all of the standards and regulations before we devised the form. As was brought up in our discussion group, this requires a great deal of interpretation. But, we try to function within all regulatory guidelines--State, Federal and Title XIX.

FUTURE DIRECTIONS IN QUALITY ASSURANCE

FRAN HOLLAND

Division of Quality Control
Medicaid Management Bureau
Health Care Finances Administration

FUTURE DIRECTIONS IN QUALITY ASSURANCE

Fran Holland

I've been asked to talk about future directions in Quality Assurance. Before doing so, I want to go back briefly and take a look at some of the things that have happened before. In particular, I want to discuss the provisions and implications of the 1972 Amendments to the Social Security Act and some of the actions taken in HEW since then. And then we can talk about the directions that we might be taking in the next few months.

I. The 1972 Amendments

Because Medicare and Medicaid costs far, far exceeded the original estimates, Congress enacted P.L. 92-603, amending the Social Security Act, in 1972. It was a very broad law that had a widespread effect on us all. Some of the key provisions of the law were as follows: First, P.L. 92-603 was the enabling legislation for the creation of Professional Standard Review Organizations (PSRO's). The intent was to involve local, practicing physicians in the on-going review and evaluation of health care services. In particular, PSRO's were given the authority for making determinations of the medical necessity for admissions and for continued stays in institutions, among a variety

of other functions. Second, P.L. 92-603 contained a requirement that the Utilization Review procedures be more objective, efficient and comprehensive; that is, it required that we use norms, standards or criteria in our utilization reviews. Third, and most crucial for Title XIX purposes, it added Section 1903(g). This section required that a state have a satisfactory program controlling utilization of institutional services; that States make a quarterly report to this effect to the Federal government and that the Federal government conduct validation surveys to assure State compliance.

Section 1903(g) also required that, if a State failed to report a satisfactory program - or if a validation survey showed a State failed to implement its program, then the Secretary must impose a penalty of 1/3 reduction of Federal matching money.

The law became effective July 1, 1973. It was not until July 1, 1977, that the first penalties were announced, which involved 20 states and totalled \$142 million. Between July 1, 1973, and the announcement of the first penalty, the Department had conducted a number of surveys to validate the State Utilization Control programs and had initiated the requirement that States forward a quarterly report confirming their UC programs. The administration recognized the

severity of the penalty provision (i.e., the all-or-none adherence and the lack of latitude for adjustment) and we are working with Congress to change the legislation.

P.L. 95-59 postponed the penalty to October 1, 1977, so that there would be time to reconsider. The Administration's Bill, HR 8095, was introduced in the summer of 1977, and it addressed two main issues of concern to us: the penalty provision and the Medical and Independent Professional Reviews (MR/IPR).

The Administration's Bill, HR 8095. With reference to the fiscal reduction provision, HR 8095 provided for:

- a reduction in the penalty, by altering the fiscal reduction to 100% FFP for each facility for which the State is not in compliance, thus relating the penalty to the extent to which the State (or institution) fails to meet the statutory standards;
- limiting the requirements subject to reduction to Utilization Review in hospitals, MR and IPR in long-term facilities;
- the application of reductions on a quarterly basis;
- eliminating requirements for quarterly reports by the State;

- Secretarial discretion to postpone the penalty for a period up to 6 months, in order to give the State an opportunity for corrective action;
- the retroactive repeal of Section 1903(g); and
- an effective date of July 1, 1978 for new legislation.

In connection with the Medical and Independent Professional Review processes, the Administration's Bill, HR 8095, proposes several major changes, as follows:

- it revokes the statutory mandate;
- it gives the MR/IPR functions to the State licensing agency;
- it requires MR/IPR findings to be used in determining certification of a facility; and
- it authorizes the use of a random sample in conducting MR/IPR reviews.

Since the writing of Administrative Bill, HR 8095, the HCFA re-organization has taken place. Under this re-organization, responsibility for legislation, policy and standards governing licensing has been removed from the Medicaid Bureau and given to the Health Standards Quality Bureau, which is also responsible for

Long Term Care and PSRO's. While MMB works with HSQB, we no longer have lead responsibility in this area.

II. Current Efforts

Our current activities are also focussed on the penalty provisions and MR/IPR. While there are a number of different proposals under consideration, they have many features in common.

Thus, with reference to the penalty provision, there is general agreement on the need for:

- reduction in the amount;
- reduction in the adherence level;
- development of an equitable formula for determining penalty;
- latitude or discretion in applying the penalty; and
- time for corrective action.

With regard to the management of quality assurance in the Long Term Area, there are a number of proposals in various stages of development. These proposals have a number of elements in common although there are some differences among them. One proposal includes the following provisions:

- revocation of the current statutory requirements for MR/IPR, with the review function to be assigned to the Licensing Agency; and

- a requirement for an in-house patient assessment, using the PACE or a similar instrument, coupled with external monitoring of a sample of resident cases.

A second proposal parallels the first as described above, except that it involves implementation on an incremental basis, spread out over several years. A third possibility involves:

- keeping the MR/IPR as a State Medicaid Agency function for the present;
- performing an impact study to assess the the relative effect of conducting sample reviews versus reviewing 100% of the residents;
- possibly requiring that quality of care standards be included in the survey and certification process; and
- developing the necessary standards and criteria for MR/IPR.

III. Future Activities

There are two main areas to be addressed. First, in connection with the penalty provision, we will pursue the areas in which there is common agreement. As discussed in relation to our current activities, these include: the retroactive repeal of Section 1903(g); reductions in the penalty and adherence levels;

and latitude for the Secretary to postpone the penalty in order to give the State an opportunity for corrective action.

Second, in terms of the role, function and administrative control of quality assurance, there are a number of key issues to be addressed:

- A decision will need to be made as to whether administrative control of the MR/IPR process should be retained by the Medicaid Agency or transferred to the survey agency;
- High priority will be given to developing quality of care standards (if quality becomes a part of the survey process) or uniform criteria for use in relation to the MR/IPR, if these reviews are retained as a separate function;
- We will also be working on the development of standards and criteria to be used in relation to assessing States' performance in controlling the utilization of institutional services. This will include a definition of what constitutes an "effective" professional review;
- A decision will be made as to whether to conduct an impact study on the MR/IPR,

to assess the effect of reviewing a sample of residents as compared with 100% reviews. The Senate Finance Committee Staff report on HR3 had recommended this earlier; and

- As has been suggested so frequently during the past two days, we will consider developing a Federal Training program in relation to the MR/IPR processes.

Changes, contained in HR 3, became law on October 13, 1977. The Administrator's Report on HR 3 is appended to these Proceedings (see page 191).

CÔNFERENCE CRITIQUE

Conference Critique

As part of a continuing effort to improve the conferences sponsored by the Institute of Medicaid Management, participants were asked to evaluate the September conference. Critique questionnaires were distributed at registration and collected during the course of the conference. Fifty percent of the participants completed the evaluation form. The summary which follows is based on a compilation of these responses.

General Assessment

Ninety-eight percent of the responding participants expressed some degree of satisfaction with the conference (eighty-five percent were well satisfied; thirteen percent were satisfied to some extent; and two percent were not satisfied).

Nearly all of the participants (ninety-eight percent) felt that the conference provided a useful forum for the exchange of information and ideas among States. Ninety percent indicated that all planned topics had been reasonably covered. Additional depth was, however, desired (by nearly thirty percent of the respondents) in relation to two major topics: addressing substantive issues in the assessment of quality and acquainting State personnel with the Federal perspective. Comments indicated that the quality assess-

ment issue was too broad and too complex to be adequately covered in the time allotted. With regard to the adequacy of information about Federal directions, there were few explanatory comments; however, it should be noted that seventy-three percent were satisfied with Federal information, a substantial increase over the level of satisfaction reported at prior conferences.

Eighty percent indicated that the conference length was about right, and all but one of the others would have preferred a longer conference.

Workshops

A significant majority (seventy-two percent) approved the existing balance between workshops and general sessions, and most of the others (twenty-two percent) would have welcomed more workshops. In general, the workshops were rated as interesting and productive, although there were several comments suggesting that more time was needed to resolve (as well as to explore) the issues raised.

Typical comments on the workshops included:

- Good exchange, informative, interesting
- Thought-provoking but not specific enough
- More issues were raised than resolved

Manual

Ninety-eight percent of the respondents felt that

the draft manual was helpful. Several, however, indicated that they would have liked to have had it sooner.

Work Features

When asked to indicate what they liked least about the conference, respondents mentioned the following items (listed in descending order of frequency):

- The physical isolation of the hotel
(Note: the conference was held at the Kansas City airport, about thirty minutes from town) and the food
- Comments about the presentations; (e.g., didn't talk on the subject; topic wasn't relevant; or speech was too general)
- Comments about the workshops; (e.g., some participants monopolized the discussion; some participants were hesitant to speak up; or leader was inadequately prepared)

None of these items was mentioned by more than seven respondents.

Best Features

When asked to identify the best features of the conference, participants expressed a tremendous variety of perceptions. Among the most common responses were:

- Sharing with other States (mentioned spontaneously by nearly a third of the respondents)

- The high caliber of the participants--State people, Federal representatives, presenters--and the breadth of representation
- The informal opportunities to communicate and the friendliness of the people
- The workshop discussions
- The efficient organization of the conference
- "Everything," "It was great," "learned a lot," etc.

Follow-up

Participants were asked which issues they would like to pursue further, and they responded with a vast array of suggestions. The most frequently mentioned topics are enumerated below:

- "How to" presentations on conducting an assessment of ICF's/MR
- More information on the regulations and how States are implementing them
- Further development of the tools for assessing quality, including suggested forms, sample completed forms, etc.
- Further development of criteria on the quality of care
- More on the specific assessment of individual plans of care

- Information on how to conduct training
- A full discussion on seclusion and restraints
- More information on the Federal perspective and on proposed legislation

In sum, participants expressed a desire to further pursue virtually every topic covered by the conference, preferably through an in-depth training program developed specifically for IPR.

DIRECTORY OF CONFERENCE PARTICIPANTS

INSTITUTE FOR MEDICAID MANAGEMENT

Conference on Assessment of Resident Care
In Intermediate Care Facilities for the
Mentally Retarded

Kansas City, Missouri

Participant List

Alexander, Suzanne M.
Department of Public Welfare
Developmental Disability Division
301 Centennial Mall
Lincoln, Nebraska 68509

Banta, Josephine
Psychiatric Nurse
SRS
Topeka, Kansas 66611

Beaufort, Patricia
Social Worker
No. Carolina Medical
Peer Review Foundation
Raleigh, No. Carolina 28216

Betts, Isla
Medical Record Administration
Kansas Neurological Institute
3107 West 21
Topeka, Kansas 66604

Blue, Donna
Resident Care Nursing Consultant
ICF/MR - State Department of
Social Security
3122 Garden Avenue
Des Moines, Iowa 51013

Bock, Warren H.
M.R. Consultant
Department of Public Welfare
Mental Retardation and
Developmental Disability Division
St. Paul, Minnesota 55155

Boggs, Charles "Ed"
Manager, Facility Services
Kentucky Department for Human
Resources
175 E. Main Street
Frankfort, Kentucky 40601

Briggs, James L.
Social Worker
Kansas State Department of
Social and Rehabilitation Services
Topeka, Kansas 66612

Bright, Charles H.
Regional Medical Program
Specialist
DHEW/HCFR/Medicaid, Region VIII
Room 11037 Federal Office Bldg.
1961 Stout Street
Denver, Colorado 80294

Brown, Matthew
Health Care Program Analyst
Medicaid Bureau/HCFR/DHEW
5600 Fishers Lane
Rockville, Maryland 20853

Burk, H.W.
Director, Professional Services
Kansas Neurological Institute
3107 W. 21
Topeka, Kansas 66604

Carastro, Joseph
Institutional Liaison
So. Carolina Department of
Social Services
Columbia, So. Carolina 29202

Cogley, Mary
Social Worker
Iowa Department of Social Services
Council Bluffs, Iowa

Conover, Tinnie B.
Utilization Review Supervisor
Virginia State Department
of Health MAP
109 Governor Street
Richmond, Virginia 23219

Cook, Ann E.
Director, Medical Social Services
Virginia Medical Assistance
Program
109 Governor Street
Richmond, Virginia 23219

Cook, Keith H.
Mental Health Coordinator
Social & Rehabilitation Services
Room 628, So. State Office Bldg.
Topeka, Kansas 66612

Cooper, Linda
Manager, Long Term Care Unit
Department of Social Services
State of Iowa, Lucas Office Bldg.
Des Moines, Iowa 50319

Cooperrider, Richard
Social Service Supervisor
Long Term Care Facility Section
Wisconsin State Division of Health
Madison, Wisconsin 53701

Decker, Robert
Administrative Director
c/o Idaho State Schools
and Hospital
P.O. Box 47
Nampa, Idaho 83651

Di Nuzzo, Anthony
Health Program Specialist
DHEW/Division Long Term Care/HCF
5600 Fishers Lane
Rockville, Maryland 20853

Dyer, Melissa
Assistant Chief/Medicaid
Nevada State Welfare Division
Medical Services
770 Crain Street
Carson City, Nevada 89701

Edwards, Michael
Technical Assistant
3rd floor, Hawarth
University of Kansas
Lawrence, Kansas 66044

Flanagan, Margaret
Hospital & Nursing Home
Coordinator
Department of Social Services
110 Bartholomew Avenue
Hartford, Connecticut 06115

Finch, Muriel
Resident Care Nursing
Coordinator
Long Term Care Unit
Medical Services Section
Des Moines, Iowa 50319

Fitzgerald, Mary Ellen
Policy & Standards Specialist
American Health Care Association
1200 15th Street, N.W.
Washington, D.C. 20005

Fugger, Sophie
P.N.I.
SRS
Box 846
Great Bend, Kansas

Giddings, Margaret
Social Services Consultant
Georgia Department of Human
Resources
618 Ponce de Leon Avenue
Atlanta, Georgia 30308

Golles, Amelia
Utilization Review Coordinator
Michigan Department of Mental
Health
6th floor, Lewis Cass Bldg.
Lansing, Michigan 48926

Graves, Jean
Social Work Coordinator
W. Virginia Welfare Department
1900 Washington Street, E.
Charleston, W. Virginia 25305

Hale, Ginger
Health Care Program Analyst
DHEW/Medicaid Bureau
330 C Street, S.W.
Washington, D.C. 20201

Hansen, Wayne
Medical Consultant
Hawaii State Medicaid
2346 Liloa Rise
Honolulu, Hawaii 96822

Hayward, Wanda
Medicaid Consultant
RN, IPRT Coordinator
Indiana State Department of
Public Welfare
100 N. Senate Avenue
Indianapolis, Indiana 46204

Hoodwin, Jean
Medical Services Program
Specialist
HCFA/Medicaid/DHEW
50 United Nations Plaza
San Francisco, California 94109

Hughes, Roy A.
Staff Assistant
Department of Institutions
Social & Rehabilitative Services
Services for the Mentally Retarded
Box 25352
Sequoyah Building
Oklahoma City, Oklahoma 73125

Humphreys, Emily
Region, II, Utilization Review
W. Virginia Welfare Department
1900 Washington Street, E.
Charleston, W. Virginia 25305

Imlau, Mary Ellen
Social Worker
Iowa Department of Social Services
Des Moines, Iowa 50319

Johnson, Charles
Teacher
Iowa Department of Social Services
112 South 18th
Clarinda, Iowa 51632

Jones, William E., Ph.d.
Superintendent
Belchertown State School
Belchertown, Massachusetts 01007

Kenaston, Sara
Program Monitoring Supervisor
State of Florida HRS
Medical Services
1323 Winewood Blvd.
Building 5, Room 125
Tallahassee, Florida 32391

Kelvey, Norma, R.N.
Principal Health Facility
Surveyor
Division of Licensure and
Construction
Rhode Island Department of Health
75 Davis Street
Providence, Rhode Island 02908

Kent, Walter
Program Specialist
Department of Human Resources
John Reagan Building
Austin, Texas 78901

Knudsen, Niels
Mental Retardation Specialist
DHEW/Region VII
6008 W. 101st Terrace
Overland Park, Kansas

Krause, Fred
Executive Director
President's Committee on
Mental Retardation
Washington, D.C. 20201

Kristola, Donald
Social Work Consultant
DHEW/HCFA
300 S. Wacker Drive
Chicago, Illinois 60606

Kuhlberg, Kenneth
Coordinator of Education
Programs
Accreditation Council for
Services/MR-D
875 N. Michigan Avenue
Chicago, Illinois 61611

Lee, Evangeline
Medicaid Consultant
Department of Human Services
509 Forest Avenue
Portland, Maine

Levinson, Lawrence
Acting Director
Institute for Medicaid Management
HCFA/Medicaid Bureau/DHEW
330 C Street, S.W.
Washington, D.C. 20201

Lewis, Marian, RN
Minnesota Department of
Health
717 S.E. Delaware Street
Minneapolis, Minnesota 55440

Lyon, Daphne
Chief, Foundation Operations
Division of Social Services
325 N. Salisbury Street
Raleigh, No. Carolina 27606

Mackie, Barbara
Nursing Care Consultant
Supervisor
Department of Social and
Health Services
Office of Nursing Home Affairs
Olympia, Washington

Maresca, Joseph
Mental Health - Mental
Retardation Specialist
Division of Analysis & Evaluation
Medicaid Bureau/DHEW
330 C Street, S.W.
Washington, D.C. 20201

Martin, Jan
Coordinator of Occupational
Therapy
Georgia Retardation Center
4770 N. Peachtree Road
Atlanta, Georgia 30338

Martin, Martha
RN/Medicaid Services
Coordinator
Medical Services NSW Division
251 Jeanell Drive
Carson City, Nevada 89701

Mathis, Ken
Teacher
Iowa Department of Social
Services
Des Moines, Iowa

Miller, Victoria
Staff Nurse
Special Medical Services
Department of Social
Rehabilitation Institutions
Sequoyah Building
Oklahoma City, Oklahoma 73105

Miner, Gina
Director Medical Record
Department
Parsons State Hospital and
Training Center
Parsons, Kansas 67357

Morrison, John
Health Educator
Illinois Department of Mental
Health & Developmental Disabilities
401 S. Spring Street
Room 402
Springfield, Illinois 62706

Ogonik, John
Assistant Director of MR
Department of Mental Health
Boston, Massachusetts 02114

Otto, Steve
Medical Services Advisor
DHEW/HCFA
601 E. 12th Street
Kansas City, Missouri 64119

Paddock, Virginia
Manager, LTC Planning and
Evaluation
DSS, Bureau of Medical Assistance
300 S. Capitol Avenue, Suite 422
Commerce Center Building
Lansing, Michigan 48926

Patterson, Gene
Consultant
Program Services, NARC
P.O. Box 6109
Arlington, Texas 76011

Patzig, Mildred
Clinical Social Worker
Patient Services Coordinator
Assistance Program - Long Term
Care Unit
Baton Rouge, Louisiana 70804

Peck, Marchell
Health Standards Survey Officer
Department of Human Resources
Atlanta, Georgia 30308

Perlowski, Stephen
Psychologist
Department of Social Services
Lucas Building
Des Moines, Iowa

Peterson, Byron
Psychiatric Social Worker
State Welfare Department
301 Centennial Mall, 5th floor
Lincoln, Nebraska 68509

Peterson, Nora
Surveyor Consultant
State Health Department
Lincoln, Nebraska 68510

Peterson, Virginia
Oregon Adult & Family Services
Salem, Oregon 97310

Phelps, Honora J.
Assistant Supervisor
Patient On-Site Review Unit
Department of Institutions,
Social & Rehabilitative Services
State Capitol, Sequoyah Building
Oklahoma City, Oklahoma 73105

Pierre, Elmer
266 Fuller Avenue, #10
St. Paul, Minnesota 55103

Radtke, Ramona
Chief, Long-Term Care Facilities
Section
Wisconsin State Division of Health
Madison, Wisconsin 53701

Radulovic, Adrienne
Program Analyst
Division of State Management
Medicaid Bureau/DHEW
330 C Street, S.W.
Washington, D.C. 20201

Rainer, "Hank" L.
Medical Social Worker
MS Medicaid Commission
Box 5160
Jackson, Mississippi 39216

Reed, Robert
Acting MEQC Chief
DHEW/HCFA
Kansas City, Missouri

Richardson, Toni
MR Facilities Coordinator
Department of Mental Retardation -
State of Connecticut
79 Elm Street
Hartford, Connecticut 06115

Roberts, Kathryn
Project Coordinator
Deinstitutionalization Model -
Project DPW
2506 Park Avenue
Minneapolis, Minnesota 55404

Roman, Sandra J.
Health Program Coordinator
Tennessee Department of Public
Health
490 Capitol Hill Building
Nashville, Tennessee 37027

Scheinost, Thomas
Program Administrator
Office of Developmental
Disabilities
Pierre, South Dakota 57501

Schuchardt, Sue, RN
Truman Medical Center
Department of Medicine
2301 Holmes Street
Kansas City, Missouri 64108

Searcey, Nancy
Long Term Care Supervisor
Nebraska Department of
Public Welfare
P.O. Box 95026
Lincoln, Nebraska 68509

Seavey, Charlene
Supervisor, Utilization Control
Minnesota Department of Public
Welfare
690 N. Robert Street
Box 30170
St. Paul, Minnesota 55175

Senary, Carol L.
Director of Social Services
State of Nevada Mental Hygiene -
Mental Retardation
4600 Kietzke Lane, Suite 108
Reno, Nevada 89502

Smith, Maudell
Specialized Consultant Nurse
Mississippi Medicaid Commission
P.O. Box 5160
Jackson, Mississippi 37716

Smith, Violet
Team Leader
Pacific Consultants
3099 Telegraph Avenue
Berkeley, California 94705

Spatz, Gerald
State Representative
HCFA/Medicaid
300 South Wacker Drive
Chicago, Illinois 60606

Stanley, Polly
Director
Nursing Home Division
938 Peachtree Street, N.E.
Atlanta, Georgia 30309

Sugrue, Joyce
Program Specialist
So. Dakota Department of
Social Services
Pierre, South Dakota 57501

Sullivan, Gary
Medicaid/Kansas City
601 E. 12th Street
Kansas City, Missouri 64106

Tsigas, Athas
Medical Services Specialist
DHEW/HCFA
36th and Market Streets
Philadelphia, Pennsylvania 19101

Vetter, Marie
Medical Services Advisor
DHEW/HCFA
601 E. 12th Street
Kansas City, Missouri 64106

Wallerstein, Edward M., M.D.
Chief, Bureau of Mental Health
Services
Division of Medical Assistance
and Health Services
324 E. State Street
Trenton, New Jersey 08625

Williams, Lankford
Medical Services Specialist
HCFA/Medicaid
50 United Nations Plaza
San Francisco, California 94109

Stewart, Jack R.
Coordinator Medicare/Medicaid
DISRS - Oklahoma
State Capitol Complex
Oklahoma City, Oklahoma 73125

Wilroy, Helen
Director,
Hudspeth
P.O. Box 26
Whitfield, Mississippi 39193

Wilson, Angus, Dr.
4992 South 938 East
Salt Lake City, Utah 84117

Phillips, Helen
Medical Services Program
Representative
Medicaid Bureau/HCFA Region X
Seattle, Washington 98101

Gardner, Anna M.
Medicaid Service Program
Representative
Medicaid Bureau/HCFA
Region X
Seattle, Washington 98101

ADMINISTRATOR'S REPORT

H.R. 3

Administrator's Report

HEALTH CARE FINANCING ADMINISTRATION

Number 2

October 17, 1977

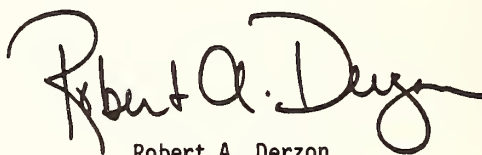
Health Care Legislation: H.R. 3, Medicare-Medicaid Anti-Fraud and Abuse Amendments

On October 13, 1977 the Congress passed H.R. 3, the "Medicare-Medicaid Anti-Fraud and Abuse Amendments." This bill is intended to strengthen the Government's capability to detect, prosecute, and punish fraudulent activities in Federal health care programs and to make other technical improvements.

The elimination of fraud and abuse in these programs is one of HCFA's highest priorities, and the enactment of H.R. 3, together with the establishment last year of the Office of the Inspector General, would greatly improve our ability to accomplish this goal. The President is expected to sign the bill in the next few days.

The provisions of H.R. 3 are focused on four major areas: strengthened program penalty sanctions, increased disclosure of information, improvements in the PSRO program, and administrative and other changes in the Medicare and Medicaid programs.

The attachment summarizes the major provisions of the bill. Unless otherwise stated, these provisions would be effective upon enactment.



Robert A. Dizon
Administrator
Health Care Financing Administration

1. STRENGTHENED PROGRAM PENALTY SANCTIONS

Increased Penalties for Fraud

The penalties for fraudulent acts under Medicare and Medicaid would be upgraded from misdemeanors to felonies, punishable by a maximum fine of \$25,000, up to five years imprisonment, or both. The charging or accepting of "contributions" as a condition for a Medicaid patient's admission or continued stay in a facility would also be classified as a felony. In addition, physicians who agreed to accept Medicare assignments and then repeatedly charged beneficiaries more than applicable cost-sharing amounts would be guilty of misdemeanors, punishable by a maximum fine of \$2,000, up to six months imprisonment, or both.

Suspension of Convicted Practitioners

The Secretary would be required to suspend from participation under Medicare (and direct the single State agency to suspend under Medicaid) a practitioner who has been convicted of a program-related criminal offense. In cases of suspension the Secretary would promptly notify the appropriate State or local licensing agency. The Secretary could permit a State to waive a practitioner's suspension from Medicaid participation if so requested. Effective date is January 1, 1978.

2. INCREASED DISCLOSURE OF INFORMATION

Disclosure of Ownership and Related Information

The bill would require providers, health maintenance organizations, and suppliers (other than individual practitioners) under Medicare, Medicaid, and the Maternal and Child Health Program, and entities providing health related services under title XX, to disclose ownership information (including information relating to subcontractors) as a condition of program participation. These disclosure requirements would also apply to Medicare intermediaries and carriers and Medicaid fiscal agents. Provider entities would also be required to disclose upon request, information concerning any significant business transactions with any subcontractor or wholly-owned supplier.

Disclosure by Providers of Owners Convicted of Fraud

The bill would require all institutions, organizations, or agencies providing services under Medicare, Medicaid, or title XX State social service grant programs to disclose to the Secretary or the appropriate State agency the name of any owners who have been convicted of fraud

against any of these programs. The Secretary or the State agency may refuse to enter into or renew any agreement or contract to provide services under these programs if there is a direct or indirect ownership or a control interest of at least 5 percent by such a convicted person. This provision would also apply to officers, directors, agents, and managing employees.

Disclosure by Providers of the Hiring of Former Intermediary Employees

A provider of services under the Medicare program would be required to notify the Secretary promptly if it employs an individual who during the preceding year was employed in a managerial, accounting, auditing, or similar capacity by the intermediary or carrier serving the provider.

Issuance of Subpoenas by Comptroller General

The bill would authorize the Comptroller General of the United States to sign and issue subpoenas in order to facilitate review of any Social Security Act program. If the individual refused to obey a subpoena, the Comptroller General could seek a court order through the Department of Justice requiring compliance.

3. IMPROVEMENTS IN THE PSRO PROGRAM

Conditional PSRO Review

The trial period for a conditional PSRO would be extended to up to 48 months (with another 24 months permitted, if the Secretary determines the PSRO is unable to perform satisfactorily for reasons beyond its control). During this period the PSRO review would apply to institutional services (including ancillary services) and any other services that the Secretary may require.

Restrictions on Reviewing Physician

The prohibition against a PSRO physician's review of services in which he has an interest would be modified to apply only to those services for which he is directly responsible, or which are furnished in a facility in which he or a family member has a significant financial interest.

Review of Ambulatory Care Services

The Secretary would be required to give priority to a request from a PSRO (including a conditional PSRO) to undertake review of services furnished in shared health facilities ("medicaid mills"). Also, within two years after it becomes fully operational a PSRO would be required to review ambulatory care services if found capable of performing such review. The Secretary could permit a PSRO to undertake such review earlier, if it so requested.

Termination of Other Review Requirements

The bill would clarify that all duplicative review activities otherwise authorized under the law would stop when the Secretary finds a PSRO (including a conditional PSRO) competent to perform review responsibilities, and that the PSRO's determinations of medical necessity and appropriateness would be conclusive for purposes of program payment.

Annual Report

The bill would require the Secretary to submit to the Congress by April 1 of each year (beginning in 1978) a detailed report on the administration, impact, and cost of the PSRO program, and remove the requirement for an annual report from the National PSR Council.

PSRO-Medicaid State Agency Relations

The bill includes several provisions, which are designed to clarify the roles of the PSRO and the State Medicaid Agency in the review of Medicaid services. In the preparation and modification of its formal plan, a PSRO would be required to consult with the State agency and to submit the plan for comment by the Governor of the State. Before its determinations become conclusive for Medicaid purposes a PSRO would be required to enter into a Memorandum of Understanding with the State Agency. The State Agency would monitor the performance of a PSRO, and the PSRO's review could be suspended if the monitoring established faulty performance. ICF review would be the State's responsibility except where the State agency is not performing such review effectively, or it requests the PSRO to assume the review.

Abolition of Program Review Team

The bill would repeal the program review team provision of the Medicare law. The functions formerly performed by such teams with respect to the quality and utilization of services would be performed by PSRO's.

Payment for Institutional Care Beyond Date Determined Medically Necessary

The bill would modify the present law provision whereby Medicare hospital and skilled nursing facility patients who are determined to need no further care in the institution are allowed an additional 3 days of benefits to give them time to arrange for their post-discharge care. The 3-day period would be reduced to 1-day where a PSRO is undertaking the review; however the PSRO could authorize up to 2 additional days on a case-by-case basis. Federal matching funds for such stays under title XIX would be subject to the same conditions.

4. MEDICARE-MEDICAID ADMINISTRATIVE AND OTHER CHANGES

Intermediary Assignments

The bill would authorize the Secretary to assign and reassign Medicare providers to available intermediaries, and to use regional and national intermediaries for a single class of providers. Before making any assignment or reassignment the Secretary would have to develop and apply standards and criteria of intermediary performance, except that any criteria may not have the effect of excluding an agency or organization solely because it operates in one State. Determinations by the Secretary would be subject to hearing and judicial review.

Payment for Durable Medical Equipment (DME)

The bill would direct the Secretary to require the purchase of DME under the Medicare program if he finds that purchase will be less costly or more practical than extended rental payments and will not impose financial hardship on the beneficiary. Payment could be made for such equipment on a lump-sum basis (or on the basis of lease-purchase arrangements, where available). Existing authority is retained for the Secretary to waive the 20 percent coinsurance for the purchase of used DME where the purchase price is at least 25 percent less than the reasonable charge for comparable new equipment. The Secretary would also be required to encourage suppliers to make equipment available on a lease-purchase basis. Effective date is October 1, 1977.

Protection of Patient Funds

The bill requires as a condition of participation in Medicare and Medicaid that a skilled nursing or intermediate care facility must establish and maintain a system to assure the proper accounting of the personal funds of patients. This system must provide for a separate account for each patient with a complete accounting of income and expenditures.

Payment for Certain Services Provided in Veterans Administration Hospitals

The bill would authorize, under certain circumstances, Medicare reimbursement to a Veterans Administration hospital for care provided to a non-veteran Medicare beneficiary where the care was provided on the mistaken (but good faith) assumption that the beneficiary was an eligible veteran. The provision would be applicable to care furnished on or after July 1, 1974.

Prohibition of Factoring Arrangements

H.R. 3 would clarify existing law to preclude the use of a power of attorney as a device to circumvent present prohibitions against the use of "factoring" arrangements in connection with the payment of claims under Medicare and Medicaid. These arrangements permit physicians and suppliers to sell their accounts receivable to bill collection agencies in order to receive more immediate payment (although at discount) for their services. This practice has frequently fostered program abuses. To reduce the undue delays in program payment which have led to factoring arrangements, the bill would require State Medicaid plans to pay 90 percent of "clean" claims (i.e., claims which do not require additional evidence) within 30 days, and 99 percent within 90 days.

Uniform Reporting System

The Secretary would be required to establish a uniform reporting system, by type of provider for Medicare and Medicaid for reporting of such items as cost of operations, volume of services, rates, capital assets, and bill data to allow for better comparison and review of provider performance. In addition, hospitals would be required to use a uniform chart of accounts, definitions, principles, and statistics in preparation of such reports.

Improvements in Medicaid Program

The bill would permit the Secretary to have the same access to records of persons and institutions that provide Medicaid services as is now provided to States to improve Federal capability to detect and prosecute fraud and abuse. To improve the State's fraud and abuse detection capability, the bill would provide Federal matching funds for States to develop independent Medicaid fraud control units. In addition, the bill amends present law to permit States to receive a higher matching rate for the operation of management information systems that provide explanation of benefits notices to recipients on a sample basis (rather than to all recipients as required under present law). The bill would also preclude Federal matching of State Medicaid expenditures that result from State laws or contracts which exclude or limit insurance benefits because an individual is eligible for Medicaid. States would also be permitted to require Medicaid recipients to assign to the State any right granted by court order for medical support or indemnification. Incentives would be provided for localities securing collections on behalf of States and States securing collections on behalf of other States.

Deferment and Waiver of Medicaid Utilization Control Penalty

The bill would waive all reductions in Medicaid long-term stay matching funds for quarters prior to January 1, 1977, which had been assessed because a State failed to meet the long-term care review requirements in

present law. Reductions for calendar year 1977 would similarly be waived if a State complied with the long-term review requirement by December 31, 1977. Applicable review requirements would be modified so that a State would be considered in compliance if it reviewed all large institutions (200 beds or more) and 98 percent of all other long-stay institutions or if a State's non-compliance was "technical" in nature. When a reduction is required, it would be determined by taking into account the proportion of Medicaid patients in institutions which were not reviewed as compared with the total number of patients in all institutions which should have been reviewed.

The bill would change the composition of the review team for skilled nursing facilities so that it could include either physicians or registered nurses (present law requires physician members). In addition, the Secretary would be required to submit a quarterly report to the Congress on his review of the State utilization control program and on any reductions that he may have imposed.

Studies

The bill would authorize two studies: (1) a comprehensive study of Medicare's claims processing operations, to be conducted by the Comptroller General of the United States, and (2) an evaluation of all home health services provided under Medicare, Medicaid, and the title XX grant programs, with a report to be submitted by the Secretary to the Congress within one year after enactment. The bill would also authorize the Secretary to develop or demonstrate improved methods for investigating or prosecuting program fraud.

DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
Washington, D.C. 20201

Official Business

Postage and Fees Paid
U.S. DEPARTMENT OF H.E.W.

HEW-392



U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
THE HEALTH CARE FINANCING ADMINISTRATION

Medicaid Bureau
HCFA 77-24539